

RESEARCH ARTICLE

# Comparisons between different elements of reported burden and common mental disorder in caregivers of ethnically diverse people with dementia in Trinidad

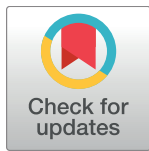
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## Abstract

### Objective

Culture plays a significant role in determining family responsibilities and possibly influences the caregiver burden associated with providing care for a relative with dementia. This study was carried out to determine the elements of caregiver burden in Trinidadians regarding which interventions will provide the most benefit.

### Methods

Seventy-five caregivers of patients diagnosed with dementia participated in this investigation. Demographic data were recorded for each caregiver and patient. Caregiver burden was assessed using the Zarit Burden Interview (ZBI), and the General Health Questionnaire (GHQ) was used as a measure of psychiatric morbidity. Statistical analyses were performed using Stata and SPSS software. Associations between individual ZBI items and GHQ-28 scores in caregivers were analyzed in logistic regression models; the above-median GHQ-28 scores were used a binary dependent variable, and individual ZBI item scores were entered as 5-point ordinal independent variables.

### Results

The caregiver sample was composed of 61 females and 14 males. Caregiver burden was significantly associated with the participant being male; there was heterogeneity by ethnic group, and a higher burden on female caregivers was detected at borderline levels of

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significance. Upon examining the associations between different ZBI items and the above-median GHQ-28 scores in caregivers, the strongest associations were found with domains reflecting the caregiver's health having suffered, the caregiver not having sufficient time for him/herself, the caregiver's social life suffering, and the caregiver admitting to feeling stressed due to caregiving and meeting other responsibilities.

## Conclusions

In this sample, with a majority of female caregivers, the factors of the person with dementia being male and belonging to a minority ethnic group were associated with a greater degree of caregiver burden. The information obtained through the association of individual ZBI items and above-median GHQ-28 scores is a helpful guide for profiling Trinidadian caregiver burden.

## Introduction

In approximately fifty years, the world will be populated by over 2 billion people 60 years or older [1]. While living longer may be considered a significant medical achievement, the major consequence is that the risk for dementia increases with age [2,3]. Accordingly, by the middle of the century, it is expected that the number of people with dementia (PwD) will increase from today's 46 million to 131 million [2,3]. While the majority receive home care by informal caregivers, this vital human resource could be on the decline [1–3]. First, worldwide, people are living longer and fertility rates are declining, which will cause a reduction in the caregiver pools [1–3]. Second, their dedication is not without consequence, as the level of stress and the burden associated with dementia caregiving is detrimental to their own health and emotional stability [4,5].

Customarily, the level of caregiver burden is determined using the Zarit Burden Interview (ZBI) [5]. Dementia caregiver-reported burden is associated with increased levels of depression and anxiety as well as increased use of psychoactive medications, poorer self-reported physical health, compromised immune function, and increased mortality [6–12]. For a number of years, much of what was known about caregiver burden was based on information obtained mainly from white North Americans [13,14]. While this provided fundamental information about the level of burden in dementia caregivers, it did not reflect essential cultural differences about caregiver experiences [15]. The percentage of elderly individuals with Alzheimer's disease and other dementias in ethnic minority groups compared to North American whites is increasing. It is thus important to understand the cultural differences in dementia caregiving and its associated burden [16]. Dementia related behaviors are more prevalent in PwD from ethnic minorities [17], making the role of caregivers even more challenging and dangerous. These individuals prefer not to use support services such as nursing homes [17]. Informal caregivers are exceptional resources for dementia care. They contribute by ensuring quality home care, reducing the time that persons with dementia PwD are institutionalized and providing an annual estimated 225 billion dollars of unpaid care [18].

Trinidad and Tobago is a high income country with a gross national income per capita of (US\$)16,2040 in 2016 and a multi ethnic population of 35.4 percent East Indian, 34.2 percent African and the remainder being of European, Chinese and mixed descent [19]. The country is also multi religious with denominations including Roman Catholic, Hindu, Anglican and Presbyterian. It is an aging nation, with more than 12 percent of the population aged 60 years

and over [19] and situated in a region of the world where the older population is expected to grow the fastest, with a projected 71% increase in the population aged 60 years or over by 2050 [19]. High levels of cardiovascular risk factors are recognized at a national level, and this is especially important since the chronic stress of caregiving may contribute to elevated biomarkers of cardiovascular risk and impaired kidney function [20,21]. It is anticipated that the predicted longevity will be accompanied by increasing numbers of cases of dementia in this nation, which already has a high prevalence of dementia [22]. It is noted that, in persons 70–89 years old in Trinidad, the prevalence of dementia exceeds the same age ranges in North America and Latin America. The lack of established residential long term and assisted living facilities and inadequate primary care and caregiving programs that target persons living with dementia results in seniors in Trinidad and Tobago having to rely primarily on family support. It is thus essential to understand how caregivers in Trinidad and Tobago are coping with the caregiver burden [19].

Numerous interventions to reduce the caregiver burden have been proposed [7,23–26]; however, cultural variations associated with the dementia caregiving experience need to be considered [14,15,27]. In particular, it is essential to establish the cultural elements of caregiving that are causing the burden. These considerations will allow health care professionals and policy makers to better meet the needs of the caregivers they serve [14,15,23,28,29]. We have previously reported preliminary findings on a group of caregivers in Trinidad [30]. In this report, we present an in-depth analysis quantifying the degree of burden reported by dementia caregivers, evaluating factors associated with a higher burden and investigating the association of different components of caregiver burden with common mental disorder symptoms in the caregiver.

## Methods

### Sample

We carried out a cross-sectional study of 75 patients diagnosed with dementia and their caregivers. Participants were recruited over a one year period through convenience sampling from a memory outpatient clinic and from Alzheimer's Association support groups. A diagnosis of dementia was confirmed by clinical assessment according to Diagnostic and Statistical Manual of Mental Disorders, 4th Edition, Text Revision (DSM IV TR) clinical diagnostic criteria [31], including administration of the Mini-Mental State Examination (MMSE) [32] and MRI or CT neuroimaging. Informed consent was obtained from all caregivers for provision of their own information and informed consent by proxy was obtained for the investigation of patient characteristics. The study was approved by the Ethics Committee of the Faculty of Medical Sciences, The University of the West Indies, St. Augustine.

### Measurements

Demographic characteristics of patients were recorded including age, gender, ethnicity, and marital status. Duration of dementia was determined from medical records, and MMSE score at assessment was considered as a covariate. Caregiver characteristics ascertained were age, gender, relationship to patient, cohabiting status, marital status, level of education, and occupation status. The Zarit Burden Interview (ZBI) [5], used to establish the degree of burden was self-administered for the most part, and caregivers were assisted only if they wanted clarification on the questions. This interview consisted of a 22-item questionnaire with a five-item response set ranging from “never” to “nearly always” graded on a scale from 0 to 4, according to the presence and intensity of an affirmative response. Its questions referred to the caregiver/patient relationship and evaluated the caregiver's health condition, psychological well-being,

finances, and social life. Although ZBI categories are often imposed to categorize levels of burden [5], mean values were used in this analysis. In addition, the 28-item General Health Questionnaire (GHQ-28) was also completed by all caregivers [33] and was categorized into a binary variable according to whether scores were below (<47) or above (47+) the sample median. This approach was carried out for pragmatic reasons, in order to define a group at risk of a mental disorder and to compare associations with different elements of caregiver burden. This followed a previously recommended approach for populations in which GHQ screening properties are not known [34].

### Statistical analyses

Stata and SPSS software were used. Having described the sample and caregiver characteristics, mean (SD) ZBI scores were compared between grouped characteristics. The median age was used a priori as a cut-off, as the sample size was too small for defining subgroups. Linear regression models were constructed in Stata and used for testing significance; nonordered exposures with 3 or more groups were entered as fixed covariates applying likelihood ratio tests, and ordered exposures were tested as ordinal covariates on one degree of freedom. Associations between individual ZBI items and common mental disorder symptoms in caregivers were analyzed in logistic regression models, with above-median GHQ-28 score as a binary dependent variable, and individual ZBI item scores entered as 5-point ordinal independent variables. Odds ratios were calculated with 95% confidence intervals and strengths of associations for ZBI items were ranked according to the Nagelkerke R<sup>2</sup> statistic derived from the logistic regression model. This R<sup>2</sup> statistic is an approximation of the proportion of variance explained—i.e., ranging from 0–1 and with higher values reflecting exposures which have a stronger potential explanatory power. For illustrative purposes, we categorized strong associations on the basis of an R<sup>2</sup> >0.20 and weak associations on the basis of an R<sup>2</sup> <0.10, with moderate associations in between these limits.

### Results

Patient and caregiver characteristics are summarized in the first columns of Tables 1 and 2. The sample of people with dementia had a mean (SD) age of 77.6 (8.3) years (range 59 to 94).

**Table 1. Patient characteristics and their associations with caregiver Zarit Burden Inventory (ZBI) scores.**

Patient characteristic		Number (%)	Mean (SD) ZBI score for caregiver	p-value
Age	<79	39 (52.7)	21.8 (16.2)	0.53
	79+	35 (47.3)	23.9 (13.1)	
Gender	Male	19 (25.3)	29.0 (14.5)	0.031
	Female	56 (74.7)	20.6 (14.3)	
Ethnicity	African	36 (48.0)	20.7 (15.2)	0.070
	East Indian	13 (17.3)	18.2 (13.6)	
	Other	26 (34.7)	27.8 (13.5)	
Marital status	Single	6 (8.2)	18.2 (12.5)	0.54
	Married	30 (41.1)	21.2 (15.0)	
	Divorced	5 (6.8)	28.2 (2.2)	
	Widowed	32 (43.8)	24.5 (15.8)	
Dementia Duration	<3 years	41 (55.4)	22.4 (15.8)	0.70
	3+ years	33 (44.6)	23.7 (13.3)	
MMSE score	>21	10 (21.7)	17.2 (12.3)	0.19
	10–21	22 (47.8)	20.6 (18.3)	
	<10	14 (30.4)	25.5 (12.0)	

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**Table 2. Caregiver characteristics and their associations with Zarit Burden Inventory (ZBI) scores.**

Caregiver characteristic		Number (%)	Mean (SD) ZBI score for caregiver	p-value
Age	50 or below	27 (36.0)	23.7 (15.8)	0.66
	>50	48 (64.0)	22.2 (14.2)	
Sex	Female	61 (81.3)	24.2 (15.1)	0.082
	Male	14 (18.7)	16.6 (11.5)	
Relation	Spouse	18 (30.0)	22.8 (13.8)	0.97
	Child	32 (53.3)	23.2 (14.8)	
	Other	10 (16.7)	22.1 (15.8)	
Cohabiting	No	24 (32.0)	20.4 (14.9)	0.35
	Yes	51 (68.0)	23.8 (14.6)	
Marital status	Never	15 (0.20)	21.9 (15.9)	0.81
	Married	41 (54.7)	22.1 (15.8)	
	Separated	14 (18.7)	23.4 (12.1)	
	Widowed	5 (6.7)	28.6 (9.8)	
Education	Primary or less	22 (29.3)	23.2 (14.1)	0.81
	Secondary	35 (46.7)	21.5 (14.5)	
	Tertiary	18 (24.0)	24.6 (16.4)	
Occupation	Full-time	32 (43.2)	20.2 (15.3)	0.52
	Part-time	3 (0.04)	17.7 (9.6)	
	Unemployed	3 (0.04)	29.0 (10.5)	
	Housewife	10 (13.5)	26.4 (12.7)	
	Retired	26 (35.1)	25.0 (15.3)	
GHQ score	<47	37 (50.0)	18.9 (13.4)	0.013
	47+	37 (50.0)	27.2 (14.7)	

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The mean (SD) estimated duration of clinical dementia was 4.3 (3.5) years (range 0.08 to 14), and the mean (SD) MMSE score was 13.0 (8.7) ranging from 0 to 26. The caregivers had a mean (SD) age of 57.3 (15.2) years (range 27 to 86), and the mean (SD) ZBI score was 24.3 (14.5), ranging from 0 to 63. ZBI scores were significantly greater for those caring for male patients and were greater at marginal levels of significance for female compared to male caregivers; higher ZBI scores were also strongly associated with above-median GHQ-28 scores in caregivers, but otherwise there were no significant associations with patient or caregiver characteristics (Tables 1 and 2).

Associations between different ZBI items and above-median GHQ-28 scores in caregivers are described and ranked in Table 3. The strongest associations were found with domains reflecting the caregiver’s health having suffered, the caregiver not having sufficient time for themselves, their social life suffering, and admitting to feeling stressed between caregiving and meeting other responsibilities. Moderate associations were found with reported strain, loss of control of life, wishing for someone else to take on the caregiving role, anger, and a feeling of dependence. Associations were weakest ( $R^2 < 0.05$ ) with reported expectations of care, feeling unable to care for much longer, uncertainty, negative effects on other relationships, lack of money, feeling that they could do a better job, fear of the future, uncomfortable having friends over, and feeling that they should be doing more.

## Discussion

It is widely accepted that providing care for a relative with dementia can be a potent source of chronic stress and can cause deleterious consequences for both the physical and emotional

**Table 3. Associations between different ZBI items and above-median GHQ-28 scores.**

ZBI item	Association with above-median GHQ-28 score	
	Odds ratio (95% CI)	Nagelkerke R <sup>2</sup>
<sup>‡</sup> Do you feel your health has suffered because of your involvement with your relative?	4.06 (2.18–7.54)*	0.39
<sup>‡</sup> Do you feel that because of the time you spend with your relative that you do not have enough time for yourself?	2.87 (1.77–4.65)*	0.33
<sup>‡</sup> Do you feel your social life has suffered because you are caring for your relative?	2.48 (1.62–3.79)*	0.31
<sup>‡</sup> Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	2.19 (1.48–3.24)*	0.26
<sup>β</sup> Do you feel strained when you are around your relative?	2.14 (1.34–3.43)*	0.17
<sup>β</sup> Do you feel like you have lost control of your life since your relative's illness?	2.21 (1.28–3.80)*	0.15
<sup>β</sup> Do you wish that you could just leave the care of your relative to someone else?	1.96 (1.16–3.23)*	0.11
<sup>β</sup> Do you feel angry when you are around your relative?	1.78 (1.16–2.79)*	0.11
<sup>β</sup> Do you feel like your relative is dependent upon you?	1.52 (1.11–2.09)*	0.11
<sup>γ</sup> Overall, how burdened do you feel in caring for your relative?	1.46 (1.03–2.07)*	0.07
<sup>γ</sup> Do you feel your relative asks for more help than needed?	1.45 (1.00–2.10)	0.06
<sup>γ</sup> Do you feel that you do not have as much privacy as you would like because of your relative?	1.46 (0.94–2.27)	0.05
<sup>γ</sup> Do you feel embarrassed over your relative's behavior?	1.45 (0.96–2.20)	0.05
<sup>γ</sup> Do you feel that your relative seems to expect you to take care of her/him as if you were the only one she/he depended on?	1.27 (0.93–1.72)	0.04
<sup>γ</sup> Do you feel that you will be unable to take care of your relative much longer?	1.30 (0.88–1.94)	0.03
<sup>γ</sup> Do you feel uncertain about what you should do about your relative?	1.27 (0.88–1.84)	0.03
<sup>γ</sup> Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?	1.38 (0.81–2.36)	0.02
<sup>γ</sup> Do you feel that you do not have enough money to take care of your relative, in addition to the rest of your expenses?	1.23 (0.88–1.74)	0.02
<sup>γ</sup> Do you feel like you can do a better job in caring for your relative?	1.20 (0.85–1.68)	0.02
Are you afraid what the future holds for your relative?	1.09 (0.79–1.50)	0.01
<sup>γ</sup> Do you feel uncomfortable about having friends over because of your relative?	1.25 (0.78–1.99)	0.01
<sup>γ</sup> Do you feel like you should be doing more for your relative?	0.99 (0.71–1.38)	<0.01

\*p<0.05

<sup>‡</sup>Strong associations (R<sup>2</sup>>0.20)

<sup>β</sup>Moderate associations (R<sup>2</sup>0.10–0.20)

<sup>γ</sup>Weak associations (R<sup>2</sup><0.10)

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health of caregivers [7–12]. The need to assess the burden on the caregiver is important since there are many associations between stress and disease. The burden of care is even more important to assess in chronic conditions such as dementia, where individuals may require long term care for as many as ten years or longer. Care activities include dealing with personal tasks such as getting dressed, bathing, and dealing with incontinence.

The preponderance of females with dementia in this study is consistent with international studies [2]. The ethnic group distribution shows some difference to that expected at a national level, with fewer participants of East Indian descent (17.3%) than 2011 Census norms (35.4%) [19]. Whether this is specific to the services sampled or reflects differences in help-seeking would require further research. It is noted that traditional East Indian families are multigenerational, suffer in silence, and do not disclose their true feelings. Similar to caregiver burden studies conducted in Latin America, China and India [10,35–37], we found that over 80% of caregivers were women, and the majority were adult children and spouses. In our sample, caregiver burden was significantly associated with the person with dementia being male and belonging to a minority ethnic group. The minority ethnic group were individuals who were not of East Indian or African descent. This is an interesting finding since previous reports that focused on ethnic and racial diversity in caregiving mention in part that caregivers of African descent (57%) were more likely to experience a greater burden from caregiving than whites (33%) [38]. In our study, whites would be part of the minority ethnic group and would be experiencing greater caregiving burden than individuals of African descent. These findings suggest that the burden is not related to the ethnicity but rather to an individual in a society belonging to an ethnicity that is in the minority. An increased level of burden was also detected in female caregivers at borderline levels of significance. Other studies have also reported increased caregiver burden in female caregivers [39–41], and it is well recognized that spouse caregivers in particular may become overburdened and depressed [39–41] as well as having an increased risk of developing dementia themselves [39–42].

Greater caregiver burden scores using the ZBI were associated with increased caregiver GHQ scores, a finding that has been reported in previous studies [43]. We specifically sought to evaluate this further in the dataset, investigating whether individual ZBI items were associated with common mental disorder symptoms to a similar extent, or whether there were some aspects of caregiver strain that were more strongly associated with mental health than others. We found that there was indeed a high level of variation in the contribution of individual ZBI items to the overall association with caregiver common mental disorder symptoms. There was heterogeneity with respect to the distribution of the items. The associations with reported health having suffered because of the caregiving role, or with feeling stressed, may reflect reverse causality (i.e., high GHQ scores rendering people more likely to report these). In our group of caregivers, 47% were either employed fulltime or part time. The association with having insufficient time for oneself may reflect not only the intensity and duration of the individual caregiving situations but also the fact that employed dementia caregivers have to make major changes in their work schedule because of their caregiving responsibilities; sixty-five percent go in late, leave early or take time off [38]. The strong association with social life having suffered is potentially important as it might be used for both screening and intervention in this community, both of which require further evaluation. It theoretically contradicts the lack of association with feeling uncomfortable having friends over and with reported negative effects on relationships with other family members; however, it is possible that some caregivers were reluctant to report these factors because of social expectations, resulting in lower item accuracy. Interestingly, concerns about privacy, embarrassment about behavior and financial worries were not significantly associated with increased GHQ score, although reported strain, loss of control, anger and dependency were associated at moderate strength.

The relatively specific associations of certain features of strain with higher common mental disorder symptoms need to be clarified in independent samples, as the analyses were exploratory; however, they suggest that particular attention needs to be given to caregivers reporting restrictions in their social activity as well as those admitting to feelings suggesting a common mental disorder, including irritability and anger as well as low mood and anxiety. Resources to

encourage sharing of the caregiving role may need to be considered as well as other means to help caregivers feel less isolated.

This study is the first to characterize caregiver burden of Trinidadian dementia caregivers. Communicating these data to health care professionals and policy makers could assist in the design of interventions that will assist our dementia caregivers to better cope with this valuable, but frequently challenging role. One of the limitations of the study is that the type of dementia and the stage of the disease were not identified, and this may also have implications for caregiver burden. As individuals progress to the end stage of the disease, they would require more supervision. The sample was also not a population-based sample but a convenient sample, which would limit generalizations about the conclusions. A future study on 'caregiver burden' would also benefit from employing qualitative methodology. However, despite this, the strength of our contribution to this area of study is that our report lays the ground work for developing possible screening test for caregiver strain in our multiethnic population.

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## References

1. Ageing in the twenty-first century: a celebration and a challenge; 2012[Cited 2018April12][Internet] Available from. <https://www.unfpa.org/sites/default/files/pub-pdf/Ageing%20report.pdf>
2. World Health Organization, Alzheimer's Disease International. Dementia: a public health priority. Geneva: World Health Organization; 2012.
3. World Alzheimer Report. The global impact of dementia; 2015. [Cited 2018April12][Internet] Available from <http://www.alz.co.uk/research/world-report-2015>



4. Zarit SH, Reeve KE, Bach-Peterson J. Relatives of the impaired elderly: correlates of feelings of burden. *Gerontologist*. 1980; 20: 649–655. PMID: [7203086](#)
5. Zarit SH, Orr NK, Zarit JM. The hidden victims of Alzheimer's disease: families under stress. New York: New York University Press; 1985.
6. Roth DL, Fredman L, Haley WE. Informal caregiving and its impact on health: a reappraisal from population-based studies. *Gerontologist*. 2015; 55: 309–319. <https://doi.org/10.1093/geront/gnu177> PMID: [26035608](#)
7. Messinger-Rapport BJ, McCallum TJ, Huger ME. Impact of dementia caregiving on the caregiver in the continuum of care. *Ann Long-Term Care*. 2006; 14: 34.
8. Schulz R, Beach SR. Caregiving as a risk factor for mortality: the caregiver health effects study. *JAMA*. 1999; 282: 2215–2219. PMID: [10605972](#)
9. Schulz R, O'Brien AT, Bookwala J, Fleissner K. Psychiatric and physical morbidity effects of dementia caregiving: prevalence, correlates, and causes1. *Gerontologist*. 1995; 35: 771–791. PMID: [8557205](#)
10. Brodaty H, Donkin M. Family caregivers of people with dementia. *Dialogues Clin Neurosci*. 2009; 11: 217–228. PMID: [19585957](#)
11. Eters L, Goodall D, Harrison BE. Caregiver burden among dementia patient caregivers: a review of the literature. *J Am Acad Nurse Pract*. 2008; 20: 423–428. <https://doi.org/10.1111/j.1745-7599.2008.00342.x> PMID: [18786017](#)
12. Prince M, Prina M, Guerchet M. World Alzheimer report 2013 journey of caring an analysis of long-term care for dementia. London: Alzheimer's Disease International; 2013.
13. Haley WE, Gitlin LN, Wisniewski SR, Mahoney DF, Coon DW, Winter L, et al. Well-being, appraisal, and coping in African-American and Caucasian dementia caregivers: findings from the REACH study. *Aging Ment Health*. 2004; 8: 316–329. <https://doi.org/10.1080/13607860410001728998> PMID: [15370048](#)
14. Pinquart M, Sorensen S. Ethnic differences in stressors, resources, and psychological outcomes of family caregiving: a meta-analysis. *Gerontologist*. 2005; 45: 90–106. PMID: [15695420](#)
15. Janevic MR, Connell CM. Racial, ethnic, and cultural differences in the dementia caregiving experience: recent findings. *Gerontologist*. 2001; 41: 334–347. PMID: [11405431](#)
16. Manly J, Mayeux R. Ethnic differences in dementia and Alzheimer's disease. In: Anderson N, Bulatao R, Cohen B, editors. *Critical perspectives on racial and ethnic differences in health in late life*. Washington, D.C: National Research Council, The National Academies Press; 2004.
17. Sink KM, Covinsky KE, Newcomer R, Yaffe K. Ethnic differences in the prevalence and pattern of dementia-related behaviors. *J Am Geriatr Soc*. 2004; 52: 1277–1283. <https://doi.org/10.1111/j.1532-5415.2004.52356.x> PMID: [15271114](#)
18. Alzheimer's Association. 2016 Alzheimer's disease facts and figures. *Alzheimers Dement*. 2016; 12: 459–509. PMID: [27570871](#)
19. CSO. Trinidad and Tobago 2011 Demographic report [Internet]. 2011; [Cited 2018April12][Internet] Available from <http://www.cso.gov.tt/sites/default/files/content/images/census/>
20. World Life Expectancy. 2017 [accessed 2018 April 12]; <http://www.worldlifeexpectancy.com/country-health-profile/trinidad-tobago>
21. Ministry of Health Government of Trinidad and Tobago. Panamerican steps chronic non-communicable disease risk factor survey: Final report. [http://www.who.int/chp/steps/TrinidadAndTobago\\_2011\\_STEPS\\_Report.pdf](http://www.who.int/chp/steps/TrinidadAndTobago_2011_STEPS_Report.pdf).
22. Davis G, Baboolal N, Mc Rae A, Stewart R. Dementia prevalence in a population at high vascular risk: the Trinidad national survey of ageing and cognition. *BMJ Open*. 2018; 8: e018288. <https://doi.org/10.1136/bmjopen-2017-018288> PMID: [29472257](#)
23. Prince MJ, Acosta D, Castro-Costa E, Jackson J, Shaji KS. Packages of care for dementia in low-and middle-income countries. *PLoS Med*. 2009; 6: e1000176. <https://doi.org/10.1371/journal.pmed.1000176> PMID: [19888456](#)
24. Schulz R, O'Brien A, Czaja S, Ory M, Norris R, Martire LM, et al. Dementia caregiver intervention research: in search of clinical significance. *Gerontologist*. 2002; 42: 589–602. PMID: [12351794](#)
25. Gitlin LN, Belle SH, Burgio LD, Czaja SJ, Mahoney D, Gallagher-Thompson D, et al. Effect of multicomponent interventions on caregiver burden and depression: the REACH multisite initiative at 6-month follow-up. *Psychol Aging*. 2003; 18: 361–374. <https://doi.org/10.1037/0882-7974.18.3.361> PMID: [14518800](#)
26. Gitlin LN. Good news for dementia care: caregiver interventions reduce behavioral symptoms in people with dementia and family distress. *Am J Psychiatry*. 2012; 169: 894–897. <https://doi.org/10.1176/appi.ajp.2012.12060774> PMID: [22952069](#)

27. Dilworth-Anderson P, Williams IC, Gibson BE. Issues of race, ethnicity, and culture in caregiving research: a 20-year review (1980–2000). *Gerontologist*. 2002; 42: 237–272. PMID: [11914467](https://pubmed.ncbi.nlm.nih.gov/11914467/)
28. Kalula S, Petros G. Responses to dementia in less developed countries with a focus on South Africa. *IFA Global Ageing*. 2011; 7: 31–39.
29. Nápoles AM, Chadiha L, Eversley R, Moreno-John G. Developing culturally sensitive dementia caregiver interventions: are we there yet? *Am J Alzheimers Dis Other Dement*. 2010; 25: 389–406. <https://doi.org/10.1177/1533317510370957> PMID: [20508244](https://pubmed.ncbi.nlm.nih.gov/20508244/)
30. Baboolal N, Davis G, McRae A. Trinidad and Tobago: a decade of dementia research. *Dement Neuropsychol*. 2014; 8: 330–338. <https://doi.org/10.1590/S1980-57642014DN84000005> PMID: [29213922](https://pubmed.ncbi.nlm.nih.gov/29213922/)
31. American Psychiatric Association. Diagnostic and statistical manual of mental disorders, 4th ed. Text Revision (DSM-IV-TR). American Psychiatric Association; 2000.
32. Folstein MF, Folstein SE, McHugh PR. "Mini-mental state". A practical method for grading the cognitive state of patients for the clinician. *J Psychiatr Res*. 1975; 12: 189–198. PMID: [1202204](https://pubmed.ncbi.nlm.nih.gov/1202204/)
33. Goldberg D. Manual of the general health questionnaire. Windsor: NFER Nelson; 1978.
34. Willmott SA, Boardman JA, Henshaw CA, Jones PW. Understanding General Health Questionnaire (GHQ-28) score and its threshold. *Soc Psychiatry Psychiatr Epidemiol*. 2004; 39: 613–617. <https://doi.org/10.1007/s00127-004-0801-1> PMID: [15300371](https://pubmed.ncbi.nlm.nih.gov/15300371/)
35. Skuse D. Care for elderly people with mental illness. *Int Psychiatry*. 2010; 7: 29–30.
36. Prince M. Care arrangements for people with dementia in developing countries. *Int J Geriatr Psychiatry*. 2004; 19: 170–177. <https://doi.org/10.1002/gps.1046> PMID: [14758582](https://pubmed.ncbi.nlm.nih.gov/14758582/)
37. Prince M, Brodaty H, Uwakwe R, Acosta D, Ferri CP, Guerra M, et al. Strain and its correlates among carers of people with dementia in low-income and middle-income countries. A 10/66 Dementia Research Group population-based survey. *Int J Geriatr Psychiatry*. 2012; 27: 670–682. <https://doi.org/10.1002/gps.2727> PMID: [22460403](https://pubmed.ncbi.nlm.nih.gov/22460403/)
38. Alzheimer's association report. 2013 Alzheimer's disease facts and figures. *Alzheimers Dement*. 2013; 9: 208–245. <https://doi.org/10.1016/j.jalz.2013.02.003> PMID: [23507120](https://pubmed.ncbi.nlm.nih.gov/23507120/)
39. Erol R, Brooker D, Peel E. Women and dementia: a global research review. 2015; [cited 2018 April 12] [Internet] Available from: <https://www.alz.co.uk/sites/default/files/pdfs/Women-and-Dementia.pdf>
40. Shriver M. A woman's nation takes on Alzheimer's. New York, USA: Alzheimer's Association; 2010.
41. Bowers K. Women and Alzheimer's disease: the caregiver's crisis 2012; [cited 2018 April 12][Internet]. Available from: [http://www.workingmother.com/sites/workingmother.com/files/attachments/2016/08/alz\\_final\\_2012.pdf](http://www.workingmother.com/sites/workingmother.com/files/attachments/2016/08/alz_final_2012.pdf)
42. Norton MC, Smith KR, Ostbye T, Tschanz JT, Corcoran C, Schwartz S, et al. Greater risk of dementia when spouse has dementia? The Cache County Study. *J Am Geriatr Soc*. 2010; 58: 895–900. <https://doi.org/10.1111/j.1532-5415.2010.02806.x> PMID: [20722820](https://pubmed.ncbi.nlm.nih.gov/20722820/)
43. Shaji KS, George RK, Prince MJ, Jacob KS. Behavioral symptoms and caregiver burden in dementia. *Indian J Psychiatry*. 2009; 51: 45–49. <https://doi.org/10.4103/0019-5545.44905> PMID: [19742206](https://pubmed.ncbi.nlm.nih.gov/19742206/)

# Dementia: is it time for targeted national screening?

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Dementia is common and burdensome with a natural history of long decline and negative impact on the duration and outcome of hospital stays and consequences for the caregiver, there has been debate in the literature about the value of population screening for dementia. This issue has been controversial. Some are of the opinion that it is important to screen since it enables the individual to make use of the function they have and plan for a future when they cannot make decisions for themselves; it also gives the family time to adjust to the developing new situation.<sup>1</sup> Others take issue with the accuracy of...

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# BMJ Open Dementia prevalence in a population at high vascular risk: the Trinidad national survey of ageing and cognition

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## ABSTRACT

**Objective** To investigate the dementia prevalence in a country with high levels of cardiovascular risk factors

**Design and methods** Older people in Trinidad are recognised to have particularly high levels of cardiovascular risk factors. We carried out a survey in a nationally representative sample of people aged  $\geq 70$  years using household enumeration. Dementia status was ascertained using standardised interviews and algorithms from the 10/66 schedule and age-specific prevalence were compared with identically defined output from the 10/66 surveys of 16 536 residents in eight other low-income and middle-income countries.

**Results** Of 1832 participants (77.0% response rate), dementia was present in 442 (23.4%). Prevalences were 12.0% in persons aged 70–74 years, 23.5% at 75–79, 25.8% at 80–84, 41.3% at 85–89 and 54.0% in those aged  $\geq 90$  years. Prevalence ratios compared with averages from 10/66 surveys in these age groups were 2.2, 2.6, 1.6, 1.7 and 1.6, respectively, and were 2.7, 2.8, 1.7, 1.4 and 0.8, respectively, compared with previously published consensus estimates for the Latin American region. Dementia was significantly associated with reported stroke and diabetes in logistic regression models adjusted for sociodemographic status and other vascular risk factors (OR (95% CI) 4.40 (2.70 to 7.19) and 1.56 (1.20 to 2.03), respectively). Projected national numbers of people with dementia (18 206) were 70%–100% higher than those estimated using most recent regional consensus prevalences.

**Conclusion** In a nation with high levels of vascular risk, dementia prevalence is higher than expected, particularly at the lower end of the 70+ age range. International prevalence projections may need to take into account risk status as well as age structures.

## INTRODUCTION

As well as having a profound impact on individuals and those who care for them, dementia is one of the most costly conditions for national health and social care systems.<sup>1–3</sup> With rapid demographic ageing occurring in both high-income and lower income nation settings, projected estimates of case numbers at regional and national levels are vital for policymaking, planning and allocation of health and welfare resources.<sup>3–7</sup> These

## Strengths and limitations of this study

- To our knowledge, ours is one of very few studies to investigate dementia prevalence in a nationally representative sample, rather than in a defined geographic catchment.
- The restriction of sampling to residents aged  $\geq 70$  (rather than  $>65$ ) years increased the numbers in older age groups and thus the precision of prevalence estimates in these age ranges.
- The study used a dementia diagnostic schedule which has been previously validated in a range of low-income and middle-income countries through the 10/66 programme.
- Response rates were reasonably high for a community survey; however, non-response bias needs to be considered when inferring prevalences.
- Although robustly validated and widely used, the 10/66 diagnostic algorithm is probabilistic and not equivalent to a clinical interview and examination; furthermore, the version used here does not seek to determine the subtypes of dementia.

projections require good quality information on the numbers of people in given age ranges and the proportions who can be expected to have dementia. However, while population age structures can be reasonably estimated and projected from national census data,<sup>8–10</sup> obtaining relevant age-specific dementia prevalence data is more challenging. Because large proportions of people with dementia remain undiagnosed, administrative data from healthcare cannot be relied on; instead, prevalences have to be inferred from epidemiological surveys with valid case-finding instruments, and because it is beyond the resources of most authorities to commission dedicated surveys, international consensus estimates have to be used.<sup>11</sup> One drawback with this approach is that, apart from broad demographic profiles, it does not take into account risk factors for dementia which may vary between populations and might influence prevalence. In particular, cardiovascular risk factors such as hypertension and diabetes

are well recognised to be associated with a higher risk of dementia at an individual level,<sup>12–15</sup> but their impact on national prevalence is not known. This is important because there is substantial national and regional variation in vascular risk factors<sup>16</sup> and in cardiovascular outcomes, such as myocardial infarction and stroke; therefore, it is problematic for a nation with high levels of vascular risk factors to be assuming dementia prevalences calculated in low-risk settings. In addition, cardiovascular risk profiles have been changing rapidly in many nations; these might well influence future dementia prevalence but the impact cannot currently be estimated.

Attempts to compare dementia prevalence between nations with different vascular risk profiles has been limited by inconsistencies in sampling and, particularly, outcome measurement. The 10/66 consortium made substantial advances through the development of a single dementia assessment protocol with established cross-cultural validity,<sup>17–19</sup> although its surveys to date have been limited to regional catchment samples rather than nationally representative populations. In order to investigate this issue further, we applied 10/66 measurement protocols in a recently conducted national survey of dementia prevalence in Trinidad and Tobago, a country recognised to have high cardiovascular risk indices: ranked 4th highest for diabetes mortality, 14th for hypertension mortality and 42nd for coronary heart disease mortality.<sup>20</sup> In addition to providing relevant information for the government, health and welfare agencies to plan adequate services for current and future cases of dementia, and to begin identifying and evaluating specific risk factors, we sought to test the hypothesis that this country with a recognised high level of vascular risk<sup>21</sup> would also have a higher than expected prevalence of dementia.

## METHODS

### Study design and sampling

A comprehensive cross-sectional survey was carried out of all residents aged  $\geq 70$  years living in randomly selected electoral enumeration districts (EDs) in Trinidad. The objective was to attain a nationally representative sample from this island; resources were not sufficient at the time to sample the smaller population of Tobago. Administrative units in Trinidad comprise 14 municipalities and 2664 EDs. A municipality is defined as a primarily urban political unit, having corporate status and powers of self-government, and an ED is a geographical area comprising approximately 150–200 households. For the purpose of this survey, 120 EDs were selected using stratified random sampling with proportional allocation to each municipality stratum. The numbers of EDs allocated to each municipality were thus proportional to the population size of the particular municipality. Sample size calculations indicated that this would be sufficient to recruit an overall sample of 2000, which would allow estimation of a typical dementia prevalence of 4.5% with a precision of  $\pm 0.9\%$ .

There were two phases to the survey. In phase I, household enumeration was conducted in the 120 randomly selected EDs, with maps provided by the Central Statistical Office to assist in the exercise. In each ED, all households were approached, field workers went door to door and inquired about individuals living in the household who were  $\geq 70$  years. In phase II, field workers revisited the specific households, that is the households with at least one resident aged  $\geq 70$  years, as identified in phase I door knocking phase, to interview index participants, informants (someone who knew a participant well) and heads of household. All enumerated individuals resident in the 120 EDs and aged  $\geq 70$  years were invited to participate. During phase I, the enumerators were advised that data collection in two of the selected EDs would be too risky because of recent crime and violence levels; therefore, two other EDs were randomly selected to replace these. At least one appropriate informant was found for all participants in the study and there were no participants for whom an informant could not be found. All participants gave informed consent or, if capacity to provide consent was lacking, this was provided by an appropriate proxy.

### Interviews

The study team consisted of a project coordinator, six supervisors and 30 field enumerators/interviewers. The latter had previously carried out enumerations and interviews on the national census and a number of other national surveys for the Central Statistical Office. All staff were trained on the instrument by one of us RS who has participated in 10/66 Consortium instrument development and research, and training covered the sampling protocol and procedures, as well as structured interviewing techniques and the specific instruments. Field interviewers were regularly checked and supervised and reported to the supervisors during the study, although there was no formal inter-rater agreement testing in this survey. Interviews were generally carried out in participants' homes and all participants received the full assessment.

### Measurements

The study used the 10/66 short dementia diagnostic schedule and accompanying algorithm. This comprises the following instruments which were administered to all participants:

1. The Community Screening Instrument for Dementia; this has been widely used in international and cross-sectional research, for example, as a component of the 10/66 schedule and in the earlier Indianapolis–Ibadan studies. The instrument comprises both an education-fair cognitive assessment and a fully structured informant interview.
2. The CERAD 10-word list learning task. An additional component of the 10/66 schedule, the task presents the word list three successive times for immediate recall, followed by a single delayed recall test after a distraction task.

3. The Euro-D scale: a fully-structured 12-item questionnaire enquiring about common depressive symptoms. It was originally developed as a means of developing a harmonised depression instrument for the EURODEP surveys of late-life mental health, where different schedules had been used, but has since been widely applied and evaluated.

The 10/66 short dementia diagnostic algorithm was applied to output from these instruments in order to ascertain presence or absence of dementia as a binary variable. The 10/66 short schedule is identical to the original 10/66 schedule<sup>22</sup> in its inclusion of the Community Screening Instrument for Dementia and CERAD 10-word list recall task, but substitutes the Euro-D depression instrument for the longer Geriatric Mental State (of which the Euro-D is a subcomponent). As recently published<sup>19</sup>, the 10/66 short schedule retains high sensitivity and specificity for dementia ascertainment (on data from 25 international centres) and was comparable to the longer instrument in dementia prevalence estimation across previous 10/66 surveys (on data from 16 536 participants in 12 sites from eight countries). All components of the algorithm and the source instruments have been published in an open access source.<sup>19</sup>

In addition to dementia status, information was obtained on the following demographic factors: age, gender, level of education (none, primary, secondary and tertiary), ethnicity (African, East Indian and mixed/other) and previous main occupation (agricultural—self-employed, agricultural—other, semi-skilled, skilled, unskilled, clerical/professional and other). A questionnaire on presence or not of the following health conditions was administered, with corroboration sought where possible from the informant: angina, heart disease, stroke, diabetes, high cholesterol and hypertension.

### Statistical analysis

Because of the proportional sampling, unweighted analyses were carried out; in addition, because the large majority of participants (83.6%) were recruited from single households, it was not felt necessary to adjust for within-household clustering. Prevalences of dementia were described according to the listed covariates and ORs calculated to describe these associations, followed by logistic regression modelling and testing of the associations between dementia and reported health conditions. We fitted a series of logistic regression models to assess the individual and joint effects of various health indicators on dementia, adjusting for demographic characteristics. In the first set of models, we fitted six separate logistic models with indicators for either angina, heart disease, stroke, diabetes, high cholesterol or hypertension as the primary predictors of interest, adjusting for age, sex and ethnicity. In the second set of models, we fitted six similar logistic models, but additionally adjusted for education and previous occupation. Finally, in a further model, we included all six health indicators and demographic

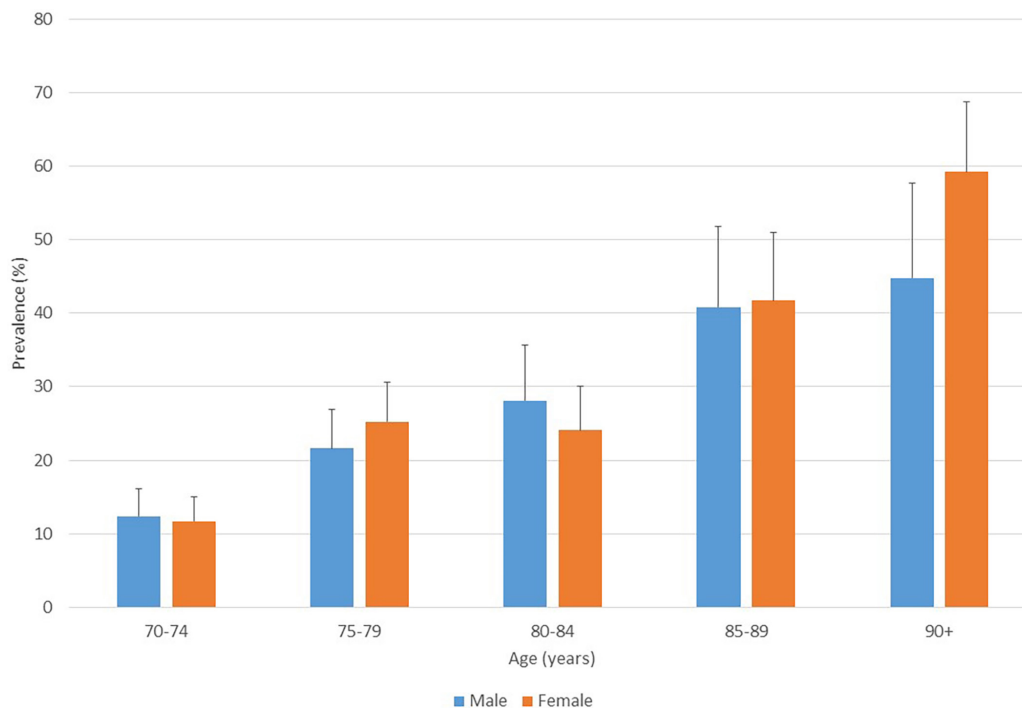
covariates to assess their joint effects on dementia. Five age groups were used for all prevalence analyses: 70–74, 75–79, 80–84, 85–89 and 90+ years. CIs for age-group-specific prevalences were provided, taking into account within-household clustering, but clustering adjustments were not employed in other analyses.

In order to contextualise prevalences in Trinidad, the 10/66 short-schedule algorithm was run, with permission, on data from previous 10/66 surveys.<sup>22</sup> Findings from these surveys have been published previously,<sup>23</sup> and data were available on 16 536 participants in 12 sites from eight countries: Cuba, Dominican Republic, Peru, Venezuela, Mexico, India, China and Puerto Rico. Prevalences from identical schedules could thus be compared across harmonised age groups. Having graphically displayed these comparisons, we calculated prevalence ratios within each age group with 95% CIs, comparing Trinidad findings with pooled estimates from the 10/66 sites. For illustrative purposes, we also described ratios comparing Trinidad findings with published consensus estimates from Latin America and USA/Canada.

We sought to estimate numbers of people with dementia in Trinidad and Tobago, in order to provide this information for national policy-makers. For the 70+ year age range sampled in the survey, we used national 2011 census numbers for men and women in the 5 year age groups defined for the survey, multiplied these by observed age-group-specific prevalences, and summed the results. We then supplemented this total with estimated numbers for the 60–69 year age group taking 2011 census population sizes for 60–64 and 65–69 year age groups and multiplying these by assumed prevalences of 1.3% and 2.4%, respectively—the most recent consensus prevalences for Latin America,<sup>24</sup> and thus judged to be the most appropriate estimates to use. The total number of people with dementia calculated using the survey data was then compared with hypothetical projections using consensus prevalences from Latin America and North America<sup>24</sup> applied to the same census strata.

### RESULTS

Of the 2378 individuals enumerated and approached, 1898 (79.8%) participated. Of these, sufficient data were available on 1832 (96.5%), 442 of whom were classified as having dementia, giving an overall prevalence of 24.1% (95% CI 22.1 to 26.1) in the 70+ year age range. The basic demographic characteristics of the interviewed sample were similar to the broader population of individuals aged  $\geq 70$  years in Trinidad and Tobago. The percentages of man and woman in the study were the same as census data with 37% of African and East Indian ethnicity compared with 34% and 35%, respectively, from census data. Concerning the EDs, mean numbers of participants per ED were 18.0 (SD 9.3; range 1–45). Prevalences by age and gender are displayed in [figure 1](#), and associations between covariates and dementia are summarised in [table 1](#). Considering demographic factors,



**Figure 1** Dementia prevalence (%) by age and gender (with upper 95% CI).

the prevalence of dementia was associated with increased age and lower education, and heterogeneity between ethnic groups (lowest in the ‘other’ category), and by previous/current occupation (highest in self-employed agricultural workers, lowest in those reporting clerical or professional occupations). No significant gender difference was found. But considering health conditions, dementia prevalence was higher only in people for whom heart disease, stroke or diabetes was reported, and was not with angina, high cholesterol or hypertension.

In logistic regression models (table 2), the associations with stroke and diabetes remained significant and relatively unaltered in strength following adjustment of demographic and other health factors.

Prevalences from the survey are further compared in figure 2 with those from 10/66 sites for identical age groups and having applied an identically derived outcome definition. Sample sizes for 10/66 surveys ranged from 546 (rural Peru) to 2885 (Cuba) with a mean of 1383 per site (16593 total). Dementia prevalence in Trinidad was observed to be higher in all age groups than those in all/most 10/66 sites, the only exception being similar or slightly higher prevalences in the 90+ years age range in urban and rural Mexico. Prevalence ratios by age group, comparing Trinidad with combined data for the 10/66 sites, were as follows: 2.44 (95% CI 1.92 to 3.10) at 70–74 years; 2.76 (2.27–3.36) at 75–79 years; 1.61 (1.31–1.98) at 80–84 years; 1.70 (1.39–2.08) at 85–89 years; and 1.58 (1.30–1.91) at 90+ years. Comparing Trinidad dementia prevalences with published international consensus prevalences (24) in the same age groups, ratios were 2.7, 2.8, 1.7, 1.4 and 0.8, respectively compared with the Latin

America region, and 3.5, 3.7, 2.2, 1.9 and 1.1, respectively compared with the USA/Canada region.

We multiplied our survey prevalences with census-derived national numbers in the specified age bands, and used international consensus prevalences to estimate additional numbers in 60–64 and 65–69 year bands, as previously described. Through this process we estimated that there were 18 206 people with dementia in Trinidad and Tobago: 10.3% of the 176 833 people aged 60+ years in the 2011 census. Hypothetical application of consensus prevalences from Latin America resulted in a projected 10 535 cases, 42% lower than our estimate, and consensus prevalences from North America projected a total number of 8748 cases (52% lower).

## DISCUSSION

In a nation recognised to have high levels of cardiovascular risk, we found high dementia prevalence in a national sample of people aged  $\geq 70$  years. Coupled with the fact that stroke and diabetes were significant risk factors, our observations are consistent with an effect of risk factor status on age-specific prevalence of dementia. Projected national numbers of people affected by dementia were substantially higher than would have been estimated from international consensus data.

To our knowledge, ours is one of very few surveys<sup>25 26</sup> of dementia prevalence in a national rather than regional survey. The Republic of Trinidad and Tobago is a twin-island state in the Caribbean, located off the east coast of Venezuela and spanning an area of approximately 5128 km<sup>2</sup>. The most recent (2011) census estimated the population to be 1 328 019 of whom 1 267 145 (95%)

**Table 1** Sample description and factors associated with dementia prevalence

Exposure	Category	Number	Number (%) with dementia	$\chi^2$ (df), P value	OR (95% CI)
Age (year)	70–74	676	81 (12.0)	163.39 (4), <0.001	Reference
	75–79	481	113 (23.5)		2.26 (1.65 to 3.09)
	80–84	330	85 (25.8)		2.55 (1.82 to 3.58)
	85–89	184	76 (41.3)		5.17 (3.56 to 7.52)
	90+	161	87 (54.0)		8.64 (5.86 to 12.7)
Gender	Male	806	183 (22.7)	1.62 (1), 0.203	Reference
	Female	1025	259 (25.3)		1.15 (0.93 to 1.43)
Education	None	139	67 (48.2)	81.8 (3), <0.001	Reference
	Primary	1231	315 (25.6)		0.37 (0.26 to 0.53)
	Secondary	253	30 (11.9)		0.15 (0.09 to 0.24)
	Tertiary	124	11 (8.9)		0.11 (0.05 to 0.21)
Ethnicity	African	686	167 (24.3)	9.04 (3), 0.029	Reference
	E Indian	686	184 (26.8)		1.14 (0.89 to 1.45)
	Mixed	412	85 (20.6)		0.81 (0.60 to 1.09)
	Other	48	6 (12.5)		0.44 (0.19 to 1.06)
Occupation	Unskilled	273	58 (21.2)	40.2 (6), <0.001	Reference
	Semiskilled	145	35 (24.1)		1.18 (0.73 to 1.90)
	Skilled	270	65 (24.1)		1.18 (0.79 to 1.76)
	Clerical/professional	423	63 (14.9)		0.65 (0.44 to 0.96)
	Other	459	134 (29.2)		1.53 (1.07 to 2.18)
	Agricultural—self-employed	113	41 (36.3)		2.11 (1.31 to 3.41)
	Agricultural—employed	149	46 (30.9)		1.66 (1.05 to 2.60)
Angina	Absent	1812	435 (24.0)	1.31 (1), 0.253	Reference
	Present	20	7 (35.0)		1.71 (0.68 to 4.30)
Heart disease	Absent	1643	383 (23.3)	5.79 (1), 0.016	Reference
	Present	189	59 (31.2)		1.49 (1.08 to 2.07)
Stroke	Absent	1752	400 (22.8)	36.8 (1), <0.001	Reference
	Present	80	42 (52.5)		3.74 (2.38 to 5.88)
Diabetes	Absent	1250	281 (22.5)	5.83 (1), 0.016	Reference
	Present	582	161 (27.7)		1.32 (1.05 to 1.65)
High cholesterol	Absent	1604	392 (24.4)	0.69 (1), 0.407	Reference
	Present	228	50 (21.9)		0.87 (0.62 to 1.21)
Hypertension	Absent	997	248 (24.9)	0.67 (1), 0.414	Reference
	Present	835	194 (23.2)		0.91 (0.74 to 1.13)

were resident in the island of Trinidad (the remainder in Tobago), with an ethnic composition of 35% East Indian and 34% African; the remainder being of European, Chinese and mixed descent. Religious denominations are similarly mixed including Roman Catholic, Hindu, Anglican, Presbyterian and Islam. Trinidad and Tobago has an ageing population, with 12% over the age of 60 years, compared with 5% in Africa and 17% in North America.<sup>27</sup>

High levels of cardiovascular risk factors are recognised at a national level. In terms of coronary heart disease mortality, Trinidad and Tobago is ranked 42nd out of 172

countries with 134.5 deaths per 100 000 per year: higher than Venezuela at 99.9, Jamaica at 77.2 and Barbados at 53.3 (20). The prevalence of diabetes in Trinidad and Tobago is one of the highest in the Americas region being 14.5% compared with 11.3% for Jamaica and 11.1% for Venezuela<sup>28</sup> According to 2014 WHO data, diabetes mellitus mortality in Trinidad and Tobago accounted for 17.1% of total deaths, and the age-adjusted mortality rate was 128.4 per 100 000 per year, ranked fourth highest in the world. Hypertension mortality accounted for 4.9% of total deaths, and the age-adjusted mortality of 36.8 per 100 000 per year was ranked 14th in the world. The 2012



**Table 2** Adjusted associations of reported health conditions and dementia

OR (95% CI)

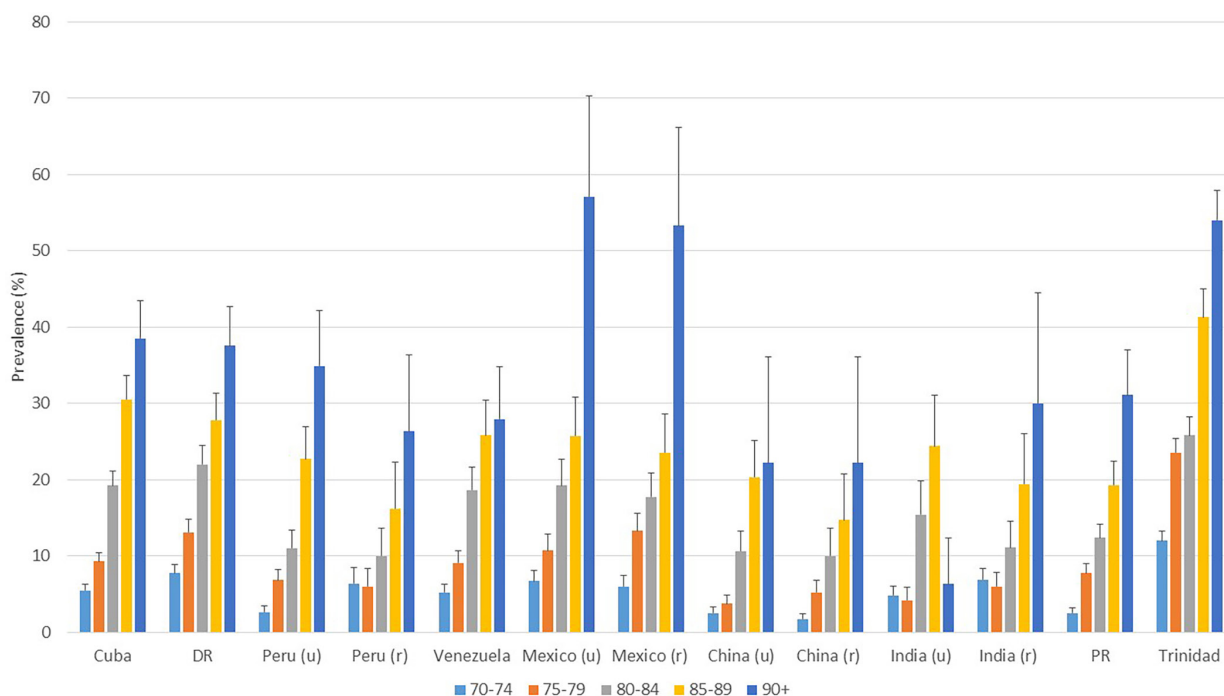
	Individually entered, adjusted for age, sex and ethnicity	Individually entered, adjusted for age, sex, ethnicity, education and previous occupation	Simultaneously entered along with model 2 covariates
Angina	1.46 (0.54 to 3.93)	1.52 (0.56 to 4.14)	1.19 (0.42 to 3.38)
Heart disease	1.29 (0.91 to 1.84)	1.22 (0.85 to 1.75)	1.21 (0.83 to 1.77)
Stroke	4.63 (2.87 to 7.48)	4.36 (2.68 to 7.09)	4.40 (2.70 to 7.19)
Diabetes	1.52 (1.19 to 1.93)	1.52 (1.19 to 1.94)	1.56 (1.20 to 2.03)
High cholesterol	1.02 (0.71 to 1.45)	1.05 (0.73 to 1.49)	0.91 (0.62 to 1.33)
Hypertension	1.02 (0.81 to 1.28)	1.00 (0.79 to 1.26)	0.85 (0.66 to 1.09)

Wald test.<sup>39</sup>

Pan-American STEPs chronic non-communicable disease risk factor survey in Trinidad and Tobago reported that 50% of individuals had a total cholesterol >190 mg/dL or were on medication for raised cholesterol, 11% were diagnosed with raised blood pressure within the last month of the survey, 30% were overweight and 34% of men smoked.<sup>21</sup> In addition, considering smoking, obesity, hypertension, poor diet and low exercise, the survey found that 65% of residents aged 45–64 years had at least three of these five risk factors.<sup>21</sup>

Dementia prevalence has been well studied in the economically developed world<sup>9 29</sup> but there have been fewer estimates from economically developing countries and, to our knowledge, all of these have been from geographic catchments rather than national samples. Population ageing is well recognised on a global scale, with particularly rapid expansions in the oldest age

ranges in many lower income settings. It is assumed that there will be a comparable increase in the prevalence of chronic age-associated diseases including dementia; however, prevalence projections have largely been calculated based on projected changes in population age structures and have assumed universal and unchanging global/regional age-specific prevalence without taking into account potential changes in risk status. Cardiovascular risk factors such as hypertension, hypercholesterolaemia and diabetes are well-established risk factors for dementia. These vary internationally and are increasing in many settings; however, the potential impact on national dementia prevalence has not been empirically investigated. Our results reinforce the necessity of local prevalence studies and highlight the risks of extrapolations from pooled regional estimates.



**Figure 2** Prevalences of dementia (%; SE bars) by age group across 10/66 consortium survey sites and the Trinidad survey derived using an identical ('short 10/66') case-ascertainment schedule.

The prevalence of dementia in persons aged 70–89 in Trinidad was particularly high: 1.5–3 times higher than estimates both from 10/66 surveys and consensus predictions. An advantage of the use of the 10/66 dementia diagnostic algorithm in our survey was that it allowed direct comparisons to be made with other 10/66 sites through applying an identical algorithm to identical instruments administered. Clearly, however, there are additional issues to consider before drawing conclusions. Regarding sampling methodology, both the Trinidad survey and all 10/66 surveys used complete enumeration of defined populations, the only difference being that these were a nationally representative random sample of districts in Trinidad, while 10/66 sites were specific geographic catchments (chosen to avoid unrepresentative communities but not assumed to be fully nationally representative). Considering non-response bias, participation rates were not dissimilar in the Trinidad survey compared with 10/66 sites (which ranged from 72% to 98%),<sup>23</sup> so this would only influence prevalence differences if non-responders had a different profile in Trinidad compared with the other surveys; this seems an unlikely scenario although data were not available on people who declined to participate. Survival bias is a consideration; however, this would only give rise to the observed higher prevalences of dementia in Trinidad if people with dementia had substantially lower mortality than people with dementia in other sites, which again seems unlikely given the high levels of vascular risk recognised at a national level.

The relatively high prevalence of dementia in Trinidad is consistent with an effect of national-level vascular risk, although clearly this conclusion can only be tentative. The prevalence in the 90+ year age group was more similar to internationally reported rates. One possible explanation is that this might reflect age-specific differences in risk effects: for example, a stronger influence of vascular risk factors in the younger age groups and a diminishing influence in those who survive longer. Raised cholesterol, either alone<sup>30</sup> or combined with smoking diabetes and hypertension at midlife,<sup>31</sup> is associated with increased risk of dementia as long as three decades later; however, cross-sectional studies have shown mixed relationships between higher blood pressure and cognition, with either no correlation or J-shaped or U-shaped associations,<sup>32</sup> and some studies have found that hypertension in late life is associated with reduced cognitive decline.<sup>33 34</sup> Differences in case mortality in dementia would also have an influence on observed international differences in prevalence, although higher case mortality would obscure rather than exaggerate the higher prevalence observed in Trinidad.

In part because of the regional variability of risk factors, the WHO in 2012 encouraged all nations to conduct prevalence of dementia investigations and to establish national dementia plans.<sup>35</sup> For example, a study in Venezuela showed that conducting nationwide prevalence studies

of dementia can provide a better picture of the impact of dementia, demonstrating that the use of international estimates to predict dementia prevalence may underestimate true numbers. In particular, the prevalence of dementia in elderly people from the Caribbean coast of Venezuela was much higher than the frequencies previously reported for developing countries.<sup>16</sup> Alzheimer's Disease International estimated that in 2010 the number of people with dementia in Trinidad and Tobago was 9000<sup>36</sup>; however, our prevalence estimates applied to 2011 national census data suggest a figure around twice as high as this, and also substantially higher than might have been estimated from regional consensus prevalences. This in turn is likely to be an underestimate, since downward-projected prevalences in the 60–64 and 65–69 year age groups are likely to be higher than the 1.3% and 2.4% estimates used, although this requires further empirical research. Also the impact of participation rate need to be taken into account. It has been reported<sup>37</sup> that population-based studies are likely to underestimate the prevalence of dementia and mild cognitive impairment especially if the participation rate is low.

A limitation in our projections was that we were not able to survey the island of Tobago; however, Tobago residents only comprise 5% of the national population and prevalences would have to differ very substantially to have a meaningful effect on estimated national numbers of people affected.

Considering strengths and limitations of the study, a key problem with many early surveys of dementia prevalence was the heterogeneity of assessments, rendering it difficult to compare between sites. The 10/66 dementia research programme was set up to address this by developing a standardised interview protocol and predictive algorithm which was valid in populations with relatively low levels of education and across cultures. For our prevalence study in Trinidad, we applied these standards, using an established diagnostic schedule and algorithm from the 10/66 programme that has been previously validated across multiple cultures and nations.<sup>38</sup> We were also able to apply the 10/66 design in surveying a national population (rather than a geographic catchment) for the first time. Our adoption of a 70+ year age cut-off clearly limits our ability to infer dementia prevalences in younger age groups; however, it was felt to be a more cost-effective means to estimate national numbers, since most people with dementia are in the upper end of the age distribution, and it allowed us to obtain reasonably precise estimates for the oldest old (eg, our sample contained 161 people aged 90+ years compared with the range of 9–96 for this age group for the listed 10/66 sites). One of the limitations of the study is that we were not able to collect blood samples or measure other markers of health status, such as blood pressure, body height and body weight. In addition, it is important to bear in mind that dementia was ascertained by a probabilistic algorithm rather than a clinical diagnosis. This approach allows for robust comparisons to be made between sites without concerns about between-clinician variability in diagnostic practice, and the algorithm itself has been evaluated against clinical diagnoses in 25 international centres<sup>17</sup>; however, precise equivalence

between algorithm-derived and clinical diagnoses cannot be assumed. Furthermore, the algorithm applied did not allow us to define or assess dementia subtypes.

Mechanisms underlying the high prevalence of dementia observed in Trinidad clearly require elucidation in more tailored research designs, and at the national level, any link between vascular risk and dementia prevalence requires confirmation in other settings. Specifically, studies need to be done to find out whether a country's 'risk status' is associated with dementia prevalence. There is however evidence of changes over time in age-specific dementia incidence rates reported from developed nation populations, which have been proposed as due to underlying generational changes in 'brain health'.<sup>29</sup> Our study, the first of its kind in Trinidad, seeks to support more tailored policy and better planning of services for a rapidly expanding older population, and we hope that the methodology can be readily transferred for wider adoption of national information gathering in the Caribbean region and elsewhere, as well as assisting in promoting dementia as a national priority.

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**Contributors** GD and NB: supervised/ trained field workers with respect to interview technique. AM: monitored field work execution by field work supervisors, reviewed completed questionnaires. RS: trained field workers on the 10/66 instrument and processed the algorithm. All authors: contributed to writing and interpretation of the results.

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**Patient consent** Obtained.

**Ethics approval** The Ethics Committee of The University of the West Indies.

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**Data sharing statement** No additional unpublished prevalence data from the study is available.

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## REFERENCES

1. Alzheimer's Disease International. *World Alzheimer Report 2010: The Global economic impact of Dementia*, 2010.
2. World Alzheimer Report 2013. An analysis of long-term care for dementia. <https://www.alz.co.uk/research/WorldAlzheimerReport2013.pdf>
3. World Alzheimer Report 2015. The Global Impact of Dementia An analysis of prevalence, incidence, cost and trends. <https://www.alz.co.uk/research/WorldAlzheimerReport2015.pdf>
4. United Nations, Department of Economic and Social Affairs, Population Division (2015). *World Population Ageing*, 2015. (ST/ESA/SER.A/390).
5. Prince M, Knapp M, Guerchet M, *et al.* *Dementia UK: update*. London: Alzheimer's Society, 2014.
6. Dementia: a public health priority 2012. World Health Organization. 2012 [http://www.who.int/mental\\_health/publications/dementia\\_report\\_2012/en/](http://www.who.int/mental_health/publications/dementia_report_2012/en/).
7. Wu YT, Fratiglioni L, Matthews FE, *et al.* Dementia in western Europe: epidemiological evidence and implications for policy making. *Lancet Neurol* 2016;15:116–24.
8. Hebert LE, Weuve J, Scherr PA, *et al.* Alzheimer disease in the United States (2010–2050) estimated using the 2010 census. *Neurology* 2013;80:1778–83.
9. Plassman BL, Langa KM, Fisher GG, *et al.* Prevalence of dementia in the United States: the aging, demographics, and memory study. *Neuroepidemiology* 2007;29:125–32.
10. Ferri CP, Prince M, Brayne C, *et al.* Global prevalence of dementia: a Delphi consensus study. *Lancet* 2005;366:2112–7.
11. Launer LJ. Counting dementia: there is no one 'best' way. *Alzheimers Dement* 2011;7:10–14.
12. Kalaria RN. The role of cerebral ischemia in Alzheimer's disease. *Neurobiol Aging* 2000;21:321–30.
13. Skoog I, Gustafson D. Hypertension, hypertension-clustering factors and Alzheimer's disease. *Neurol Res* 2003;25:675–80.
14. Kalaria RN, Maestre GE, Arizaga R, *et al.* Alzheimer's disease and vascular dementia in developing countries: prevalence, management, and risk factors. *Lancet Neurol* 2008;7:812–26.
15. Rizzi L, Rosset I, Roriz-Cruz M. Global epidemiology of dementia: Alzheimer's and vascular types. *Biomed Res Int* 2014;25:1–8.
16. Molero AE, Pino-Ramírez G, Maestre GE. High prevalence of dementia in a Caribbean population. *Neuroepidemiology* 2007;29:107–12.
17. Prince M, Acosta D, Chiu H, *et al.* Dementia diagnosis in developing countries: a cross-cultural validation study. *Lancet* 2003;361:909–17.
18. Prince M, Bryce R, Albanese E, *et al.* The global prevalence of dementia: A systematic review and metaanalysis. *Alzheimer's & Dementia* 2013;9:63–75.
19. Stewart R, Guerchet M, Prince M. Development of a brief assessment and algorithm for ascertaining dementia in low-income and middle-income countries: the 10/66 short dementia diagnostic schedule. *BMJ Open* 2016;6:e010712.
20. World Life Expectancy 2017. <http://www.worldlifeexpectancy.com/world-health-rankings> (accessed 18 May 2017).
21. Ministry of Health Government of Trinidad and Tobago. Panamerican steps chronic non-communicable disease risk factor survey: Final report. [http://www.who.int/chp/steps/TrinidadAndTobago\\_2011\\_STEPS\\_Report.pdf](http://www.who.int/chp/steps/TrinidadAndTobago_2011_STEPS_Report.pdf).
22. Prince M, Ferri CP, Acosta D, *et al.* The protocols for the 10/66 dementia research group population-based research programme. *BMC Public Health* 2007;7:165.
23. Llibre Rodriguez JJ, Ferri CP, Acosta D, *et al.* Prevalence of dementia in Latin America, India, and China: a population-based cross-sectional survey. *Lancet* 2008;372:464–74.
24. Prince M, Bryce R, Albanese E, *et al.* The global prevalence of dementia: a systematic review and metaanalysis. *Alzheimers Dement* 2013;9:63–75.
25. Langa KM, Larson EB, Crimmins EM, *et al.* A comparison of the prevalence of dementia in the United States in 2000 and 2012. *JAMA Intern Med* 2017;177:51–8.
26. Wu YT, Beiser AS, Breteler MMB, *et al.* The changing prevalence and incidence of dementia over time – current evidence. *Nat Rev Neurol* 2017;13:327–39.
27. Global Age Watch Index 2013, Purpose, methodology and results. [www.helpage.org](http://www.helpage.org) (accessed 18 May 2017).

28. <https://idf.org/our-network/regions-members/north-america-and-Caribbean/welcome.html> (accessed 18 May 2017).
29. Matthews FE, Stephan BC, Robinson L, *et al.* A two decade dementia incidence comparison from the Cognitive Function and Ageing Studies I and II. *Nat Commun* 2016;7:11398.
30. Solomon A, Kivipelto M, Wolozin B, *et al.* Midlife serum cholesterol and increased risk of Alzheimer's and vascular dementia three decades later. *Dement Geriatr Cogn Disord* 2009;28:75–80.
31. Whitmer RA, Sidney S, Selby J, *et al.* Midlife cardiovascular risk factors and risk of dementia in late life. *Neurology* 2005;64:277–81.
32. Birns J, Kalra L. Cognitive function and hypertension. *J Hum Hypertens* 2009;23:86–96.
33. Kennelly SP, Lawlor BA, Kenny RA. Blood pressure and the risk for dementia: a double edged sword. *Ageing Res Rev* 2009;8:61–70.
34. Corrada M, Hayden KM, Bullain SS, *et al.* Age of onset of hypertension and risk of dementia in the oldest-old: The 901 study. *Alzheimers & Dementia* 2014;10(4Suppl):501.
35. World Health Organization. Dementia: A public health priority 2012. <https://extranet.who.int/agefriendlyworld/wp-content/uploads/2014/06/WHO-Dementia-English.pdf> (accessed 10 May 2017).
36. Dementia in the Americas: Current and Future Cost and the Prevalence of Alzheimer's Disease and other Dementias. Alzheimer's Disease International. <https://www.alz.co.uk/sites/default/files/pdfs/dementia-in-the-americas-ENGLISH.pdf> (accessed 18 May 2017).
37. Noguchi-Shinohara M, Yuki S, Dohmoto C, *et al.* Differences in the prevalence of dementia and mild cognitive impairment and cognitive function between early and delayed responders in a community-based study of the elderly. *J Alzheimer's Dis* 2013;37:691–8.
38. Prince MJ. The 10/66 dementia research group -10 years on Indian. *J Psychiatry* 2009;51(Suppl 1):S8–15.
39. Judge GG, Griffiths WE, Hill RC, ed. *The Theory and Practice of Econometrics*. 2nd. New York: Wiley, 1985.

# Trinidad and Tobago

## A decade of dementia research

Nelleen Baboolal<sup>1</sup>, Gershwin Davis<sup>2</sup>, Amanda McRae<sup>3</sup>

**ABSTRACT.** In 2003, academic staff members at The University of the West Indies Faculty of Medical Sciences St Augustine Trinidad and Tobago combined their expertise to make strides in Alzheimer's and Dementia research in Trinidad and Tobago. Dr. Nelleen Baboolal, Dr. Gershwin Davis and Professor Amanda McRae began developing a project that has produced significant results by examining not only the epidemiology of dementia, but the associated risk factors; caregiver burden and ultimately establishing biomarkers for the disease. This review is an account of our results from a decade of dementia research and how they are contributing toward mitigating the dementia tsunami in Trinidad and Tobago.

**Key words:** caregiver burden, biomarkers, dementia prevalence socioeconomic impact.

### TRINIDAD E TOBAGO: UMA DÉCADA DE PESQUISA DEMENTIA

**RESUMO.** Em 2003, os membros da equipe acadêmica da Faculdade de Ciências Médicas St Augustine, da Universidade de West Indies, Trinidad e Tobago, combinaram seus conhecimentos para promover avanços nas pesquisas sobre doença de Alzheimer e demência em Trinidad e Tobago. Dr. Nelleen Baboolal, Dr. Gershwin Davis e Professora Amanda McRae começaram a desenvolver um projeto que tem produzido resultados significativos através da análise não só da epidemiologia da demência, mas também dos fatores de risco associados, sobrecarga do cuidador e, ultimamente, estabelecendo biomarcadores para a doença. Esta avaliação representa um relato de nossos resultados de uma década de pesquisa demência e como eles estão contribuindo para mitigar o tsunami de demência em Trinidad e Tobago.

**Palavras-chave:** sobrecarga do cuidador, biomarcadores, a prevalência de demência impacto socioeconômico.

### INTRODUCTION

The Republic of Trinidad and Tobago is a twin island state located at the southernmost tip of the Caribbean archipelago. Its multi-ethnic population of approximately 1.3 million consists of East Indian 40.3%; African 39.6%; mixed 18.4%; and 1.7% belong to other ethnic groups.<sup>1</sup> Ethnic differences have been observed in many important complex chronic illnesses and acute infections. There is an established predominance of early-onset diabetes mellitus in the South Asian population and a higher prevalence and severity of hypertension in African citizens.<sup>2</sup> There is an increase in metabolic syndrome across all ages of the population. Furthermore and highly significant, is that Trinidad and Tobago is an ageing population. At present, the

elderly population of Trinidad and Tobago stands at 13 percent or 177,676 persons over the age of 60 years.<sup>1</sup> This figure is expected to increase to 17.7% by 2025. In essence, this population resides amid an arsenal of risk factors currently considered to potentiate cognitive decline. As the population of the Trinidad and Tobago ages there is a need to prepare the policy makers for what could be considered a cognitive deficit tsunami. One can ask: are we ready for the social and physical changes that accompany aging?

For many, dementia remains a stigma. Consequently, the elderly may have a tendency not to report early symptoms of memory loss. This can even extend to family members who may be reluctant to accept or report that an elderly relative is displaying cognitive de-

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cline. As the population ages it is essential to prepare the population for the road ahead.

There have been some improvements in this direction with the establishment of eight senior activity centers and organizations such as the Senior Achievers, Golden Years and the Trinidad and Tobago Association for Retired Persons and the Alzheimer's Association of Trinidad and Tobago. These social organizations are essential for mental stimulation and to decrease loneliness.

Epidemiological data is fundamental to optimize planning of services and policy.<sup>3,4</sup> The absence of functional and reliable data collection is obscuring the reality of dementia in this region. There has been a gross underestimation of the number of cases of dementia in the country, as many patients with dementia live at home they are not being accounted for.

Furthermore, there is growing concern about caregivers. Many caregivers have no knowledge about the clinical features of the disorder. Therefore they are ill-prepared to cope with the behavioral changes which accompany the progression of dementia. This group needs to be educated about the frustration and exhaustion encountered by caring for an elderly relative with dementia. Many caregivers are elderly themselves.

Delaying the onset of Alzheimer's disease is a high priority for any given population. Identifying strategies to slow down the progression of AD as well as other aged-related cognitive disorders has become a collective world-wide mission. Progress has been made to decipher areas which have the potential to lower the risk of AD. Simple interventions including diet, education, exercise, and increasing cognitive activity are among several factors recently considered ways of reducing the risk of Alzheimer's disease. Thus, it is important for a given population to identify risk factors which may be pertinent to their region and environment, thereby allowing interventions to slow down the onset of dementia.

Trinidadians are at great risk for dementia. Firstly, there is a high prevalence of diseases which are risk factors for dementia.<sup>2</sup> Secondly, the World Health Organization has estimated that the prevalence of Dementia in the Caribbean and Latin America is the highest in the world.<sup>5</sup>

What is being done in Trinidad and Tobago to mitigate the dementia tsunami? To this end, the present review will provide an account of the efforts of three academic staff members at the University of the West Indies at the Faculty of Medical Sciences to help prepare the population and policy makers for this tsunami.

## RESEARCH TEAM

One could consider that this is a result of being at the

right place at the right time. The University of the West Indies promotes research and specifically encourages faculty members to form research clusters. This was the case for Dr. Nelleen Baboolal, Senior Lecturer in Psychiatry, Dr. Gershwin Davis, Senior Lecturer in Chemical Pathology, and Professor Amanda McRae, Professor of Human Anatomy who had individually conducted dementia research. We met and decided to pool our expertise in order to make strides in Alzheimer's and Dementia research in Trinidad and Tobago.

For the last decade we have consistently held research meetings on Wednesdays. Our dedication and commitment to dementia research has indeed been very rewarding. We began developing a four-stage project that could yield breakthrough results by examining not only the epidemiology of Dementia, but the associated risk factors; caregiver burden and ultimately establishing biomarkers for the disease. This is a collaborative effort not on a specific project but on the theme of Alzheimer disease and Dementia and Mild Cognitive Impairment (MCI). To that end, we established and incorporated Dementia Awareness and Research of Trinidad and Tobago (DARTT) which is a voluntary non-profit organization which aims to educate the population, promote brain health, diagnose afflicted persons, support patients, families and caregivers, conduct research on Alzheimer's disease and establish the prevalence of dementia and its economic burden.

In 2003, a very successful memory clinic was established at a tertiary teaching hospital. This provided the infrastructure for both clinical and basic research. Patients were seen and clinical evaluations, blood and neuro-radio imaging investigations and assessment of caregivers were done.

Another successful approach from our collaboration has been outreach. We have all participated in several local TV programs aimed at promoting dementia research and extending awareness of dementia to the general population.

Realizing that several of our research projects would need age-matched control subjects we made contact with organizations such as the Senior Achievers and the Golden Years. Both of these organizations are composed of dynamic seniors aged 60 and above. We were invited to their monthly meetings to address issues related to dementia and its awareness. They all agreed to take the Mini-Mental State Exam (MMSE)<sup>6</sup> and donate blood samples. We arranged a day at each organization and administered the MMSE. Blood samples were taken on a different day. Another organization where we have had a conspicuous presence is the Alzheimer's Association of

Trinidad and Tobago (AATT) where we interacted with a monthly support group for caregivers. In addition to caregivers at Dr. Baboolal's memory clinic, we have also administered caregiver questionnaires to those attending the AATT. Furthermore, we have played active roles in events organized by the AATT during Alzheimer's awareness month in September.

In 2005, we also launched a MPhil/PhD Neuroscience degree at the University of the West Indies, the first such degree program in the English-speaking Caribbean. Our first PhD Neuroscientist graduated in 2014.

Additionally, between 2011 and 2013 the research of two graduate students, who completed the Masters in Public Health at the University of the West Indies, was supervised by Dr. Baboolal. Their research projects examined "The Plight of the Caregiver: A Study of the Burden Placed upon Caregivers of Patients with Dementia in Trinidad" and "The Prevalence of depression among the Elderly who attend Senior Activity Centres in Trinidad".

From the very outset of our collaboration, Dr. Baboolal considered that one of the most important achievements from our group would be to establish the prevalence of dementia and its economic impact in Trinidad and Tobago. Determining a central figure such as the prevalence of dementia in Trinidad and Tobago is critical because for the first time, it will provide the Government, and anyone else who wants to know, with a picture of how common dementia is and the socio-economic cost that comes with it. Results will also have enormous transformative implications for policy, as they will highlight the economic reasons for investing in dementia. Though we realized how essential it was to establish the nationwide prevalence of dementia and its economic impact in Trinidad and Tobago, organizing this project, including funding, took several years and in fact the project actually began in 2012. While we were preparing for the nationwide prevalence study, we conducted a prevalence of dementia investigation in persons attending senior activity centers, those in nursing homes, and persons collecting welfare checks.

Professor. R. Stewart of the Institute of Psychiatry, King's College, London has been instrumental in guiding us with the preparations of the prevalence of dementia study. He has conducted several workshops and will analyze the data.

In view of the high prevalence of diabetics in Trinidad and Tobago,<sup>2</sup> we also investigated cognitive function in type 2 diabetic patients. This collaboration benefited from the expertise of Professor S. Teelucksingh of The University of the West Indies.

Our collaborative efforts have generated several publications, book chapters, workshops and conference presentations at international conferences, including the International Conference on Alzheimer Disease, Vas Cog, American Association of Clinical Chemistry Conference and Caribbean Health Research Conference.

Our major research accomplishments include:

Biomarkers, cognitive assessment in diabetic patients, caregiver burden, prevalence of dementia in three different settings, and the nationwide prevalence and economic impact of dementia in Trinidad and Tobago. The sections below provide a synopsis of results obtained from some of these various research themes.

## BIOMARKERS

One key facet of the project of our group is developing a serum screening biomarker for the disease that could introduce a paradigm shift in the way we approach the healthcare maintenance of the elderly. This is due to the fact that a serum marker would provide a universal means to differentiate Alzheimer's Disease (AD) from other dementias, as well as establish early detection of the disorder.

The Trinidadian population may have a raised risk for dementia because hypertension, diabetes and cerebrovascular disease are common.<sup>2</sup>

Based on the high prevalence of the above disorders we chose to investigate factors which could predict or assist in discriminating types of dementias in our population from healthy seniors.<sup>7</sup>

We selected the amino acid homocysteine (tHcy), C-reactive protein (CRP) and serum sialic. Elevated circulating levels of homocysteine are an independent risk factor for stroke.<sup>8</sup> Furthermore, elevated levels of tHcy have been linked to cognitive decline.<sup>8,9</sup> CRP is considered to have a link to cardiovascular disorders and has been investigated in relationship to the development of certain dementias.<sup>10</sup> Serum sialic acid is a potent cardiovascular and renal risk factor as it is increased in cerebrovascular disease and in patients with micro- and macro-vascular complications of diabetes.<sup>11</sup> In view of the relationship of sialic acid to disorders considered risk factors for dementia, it may also be a predictor of cognitive decline.

The investigation included 51 healthy elderly individuals who were members of a seniors group plus 27 persons with dementias of the Alzheimer's type (AD), persons with Alzheimer's disease or persons with pure vascular dementia (VaD). The MMSE was administered and all patients were subjected to interview, physical examination and neurological examination. The clini-

cal/biochemical characteristics of both groups were compared.

Plasma tHcy was determined on the Abbot AxSym using FPIA. Serum CRP concentrations were measured using the Tina-Quant sCRP (Latex) high sensitive immunoturbidimetric assay on the Roche/ Hitachi 912 Automatic Analyzer. Serum sialic acid was measured by spectrophotometric assay using standard chemicals and reagents. For the dementia patients, the main clinical diagnoses were AD, 18 (67%) and VaD, 9 (33%).<sup>7</sup>

When the controls were compared with all patients as a group, the MMSE and sialic acid differed significantly, with MMSE scores being higher and sialic acid levels lower in controls. Patients with AD had significant differences in the MMSE scores and sialic acid scores, but not for tHcy and CRP values when compared with controls. In patients with VaD however, significant differences were obtained for both MMSE scores and tHcy but not for sialic acid or CRP.

Several research studies have shown that the concentration of sialic acid in serum is elevated in pathological states when there is damage to tissue, tissue proliferation and inflammation. The latter has in recent times reemerged as an important aspect of the pathogenesis of Alzheimer disease.<sup>12</sup> Our findings suggest that elevations in serum sialic acid levels could be related to AD pathology. In this regard, it is of interest that a recent study<sup>13</sup> has demonstrated that reduction in sialic acid protects PC 12 cells from B amyloid toxicity. From a speculative point of view, the elevated levels of sialic acid may reflect an increase in the deposition of B amyloid. Further studies are necessary to elucidate the relationship between elevated sialic acid levels and ongoing AD pathology.

The finding that sialic acid levels were significantly higher in patients with AD compared to controls and not different with respect to VaD is unlike the results for tHcy, where notable differences were found between VaD and controls. This suggests that there may be different mechanisms at work in the pathogenesis of the two conditions.<sup>7</sup>

We have also identified another biomarker which appears to have diagnostic potential. Previous studies have demonstrated that the cerebrospinal fluid (CSF) from AD patients contains an antibody directed against microglia (MgAbs).<sup>14</sup> The rapidly expanding field of neuroinflammation has revealed that immunocompetent microglia play an early role in the events leading to AD pathology.<sup>15</sup> It should be remembered that a biomarker is a substance such as an antibody or protein, which is usually present in either the cerebrospinal fluid

or blood. According to the criteria of the Consensus Report of the Working Group on Molecular and Biochemical Markers of AD, an ideal biomarker should: be able to detect a fundamental feature of AD neuropathology; and be validated in neuropathologically-confirmed AD cases; be precise (able to detect AD early in its course and distinguish it from other dementias); reliable; non-invasive; simple to perform; and inexpensive.<sup>16</sup> Thus, it appears reasonable to propose that MgAbs could be a potential biomarker for AD.

This antibody has shown in both clinically<sup>14</sup> and neuropathologically confirmed AD cases<sup>17</sup> to be present at a greater frequency in the CSF compared to other dementias. Among patients in Trinidad and Tobago, we further demonstrated that serum MgAbs can distinguish AD from healthy age-matched controls.<sup>18</sup> There was no significant difference between the presence of MgAb in VaD patients compared to controls.<sup>18</sup>

For us, an exciting milestone was reached in 2008, after conducting a workshop entitled "Biomarkers for Dementia. Is there a role?" at the American Association of Clinical Chemistry Conference in Washington DC. This attracted the attention of a major UK-based diagnostic company. Subsequently, collaboration developed between this company and the UWI to further the development of MgAbs as a diagnostic biomarker for Alzheimer's disease.

This collaboration was pursued. We identified major histocompatibility complex 1 (MHCI) as the microglial surface antigen to which autoantibodies are directed in AD patients. ELISAs were established using two distinct forms of MHCI as the antigen. One form was HLA-A\*0201, the most commonly expressed form of MHCI in humans, whilst rat RT1.A<sup>1</sup> was also used to provide a more direct comparison with the rat brain cross-sections previously employed for immunocytochemistry. Data was analyzed by constructing receiver operator characteristic (ROC) curves. When the cerebrospinal fluid (CSF) samples from the cohort of 20 patients with Alzheimer's disease and the 20 individuals without Alzheimer's disease were tested on the newly developed ELISA platform there was a clear and statistically significant association between the presence of anti-MHC1 antibodies and the presence of Alzheimer's disease. Using RT1.A as the antigen in the ELISA, the area under the curve (AUC) was 0.756 ( $p=0.0004$ ) and when using HLA-A\*0201 as the antigen the AUC was 0.705 ( $p=0.0071$ ). The ROC curve analysis suggested that for the CSF we have a new ELISA test that is at best good at distinguishing AD patients from controls (Figure 1). This test should be studied not only in patients



with Alzheimer’s disease but also in other groups of patients such as those classified as MCI. Further work is in progress to establish an ELISA test for serum MgAbs.

### COGNITIVE TESTING IN DIABETES MELLITUS PATIENTS

The elevated prevalence of diabetes mellitus in Trinidadian citizens is an indication that a large part of the population is at risk of developing dementia. It has been established that patients with diabetes have increased deposition and decreased clearance of amyloid,<sup>19</sup> as well as increased incidence of hypoglycemia and hyperglycemia which contributes to cognitive impairment. Patients with a diagnosis of diabetes have nearly double the risk of developing both dementia and mild cognitive impairment compared to non-diabetics in the elderly population.<sup>20</sup> In view of the link between diabetes mellitus and cognitive decline, we considered that it would be relevant to investigate cognitive function in patients with diabetes mellitus in Trinidad and Tobago. There were 96 patients with type 2 diabetes mellitus and 87 age-matched non-diabetic controls in this study. Demographic data was obtained from both diabetic patients and healthy age-matched controls.

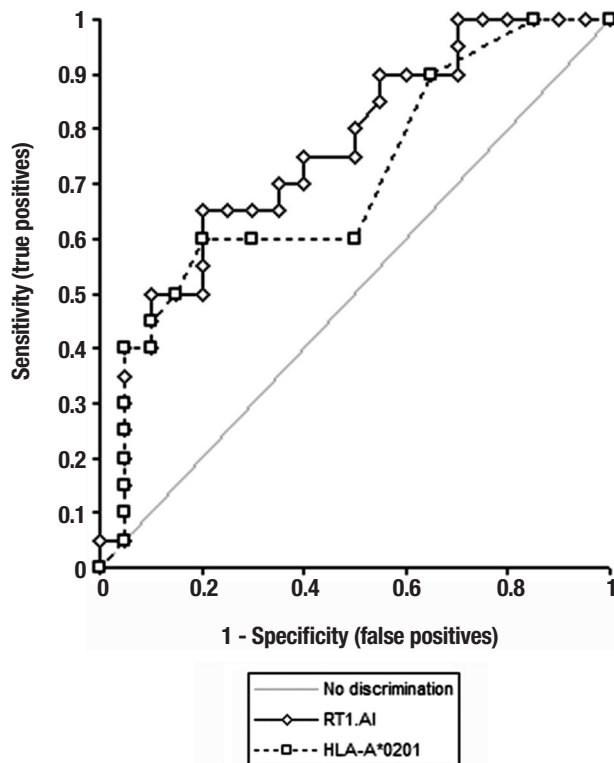
In order to determine normal cognitive function, MCI, or dementia the following tests: Addenbrooke’s Cognitive Examination Revised (ACE-R), MMSE (Mini-Mental State Exam), Color trails-1, Color trails-2, Picture-Number Matching, Word Recall and Digit Span Forward and Backward were administered to both patients and controls.

Of all these tests, only performance on the ACE-R - a brief cognitive screening instrument sensitive to early stages of dementia- was significantly different when comparing persons with diabetes to controls.

These findings suggest that the ACE-R could be a useful screening test in primary care for detecting the presence of early cognitive dysfunction in diabetics. The MMSE was not sensitive enough to pick up mild cognitive impairment in Diabetic patients.

### CAREGIVING IN TRINIDAD AND TOBAGO

Dementia and cognitive impairment are the leading chronic disease contributors to disability, and particularly dependence, among older people worldwide. The need for support from a caregiver often starts early in the dementia journey, intensifies as the illness progresses over time, and continues until death.<sup>21</sup> Caregivers include family, friends, as well as community and paid caregivers who may or may not be family. The World Alzheimer Report 2013 reveals the global Alzheimer’s



**Figure 1.** ROC curves using RT1.A1 and HLA-A\*0201 as the antigen. As shown when the data was analyzed by constructing receiver operator characteristic (ROC) curves, using RT1.A1 as the antigen in the ELISA, the area under the curve (AUC) was 0.756 (p=0.0004) and when using HLA-A\*0201 as the antigen AUC was 0.705 (p=0.0071). The (ROC) shows the effectiveness of the new ELISA test in discriminating between true cases of disease from non-disease. The maximum value for AUC 1 indicates a perfect test and a value of 0.5 - the straight line through zero - indicates no discriminative value.

epidemic is creating a shortage of caregivers and lack of support for family members.

Unpaid care for persons with dementia is provided by family, friends and community, and care is generally referred to as ‘informal’ care. Paid care is referred to as ‘formal’ care. Family caregivers and paid caregivers share much in common. They all carry out difficult, demanding and socially useful roles, with minimal training and preparation. In Trinidad and Tobago, a significant number of persons suffering from dementia are cared for at home by an informal caregiver. Caring for a person with AD and other dementias is associated with significant risk to the caregiver’s health and well-being.<sup>22</sup>

The term “caregiver burden” is used to describe the physical, emotional and financial cost of providing care.<sup>23</sup> The Zarit Burden Interview (ZBI) is a standardized, validated, reliable tool for assessment of the burden of caregivers for dementia patients.

There has been no assessment of caregiver burden in Trinidad and Tobago. Thus, we administered the ZBI to caregivers to evaluate the degree of burden in caregivers of dementia patients in a Trinidadian population. The ZBI was developed by Zarit and co-workers in 1985<sup>24</sup> and comprises a 22-item questionnaire with a five-item response set ranging from “never” to “nearly always” graded on a scale from 0 to 4, according to the presence or intensity of an affirmative response. Based on the total score, individuals were classified as having little or no burden (0-20), mild to moderate burden (21-40), moderate to severe burden (41 to 60), or severe burden (61-88). The questions refer to the caregiver/patient relationship and evaluate the caregiver’s health status, psychological well-being, finances, and social life. The caregiver burden is evaluated by means of the total score obtained from the sum total of questions. We also included an evaluation of the possible risk factors associated with higher burden. The effects of different factors including patient and caregiver age, gender, years of education, relationship between the patient and caregiver as well as the patient’s symptom duration and degree of cognitive impairment were investigated.

Informed consent was obtained from all caregivers and informed consent by proxy was obtained for the investigation of patient characteristics. Seventy-five patients diagnosed with dementia along with their caregivers were included in the study. Patients were diagnosed using the DSM IV TR,<sup>25</sup> the MMSE,<sup>6</sup> clinical evaluations, laboratory investigations and brain CT or MRI. Demographic characteristics of patients and their caregivers were recorded

The GHQ-28 was administered to all caregivers. It contains 28 items that, through factor analysis, have been divided into four sub-scales. The GHQ-28 is the most well-known and popular version of the GHQ. It is used to detect psychiatric disorder in the general population and within community or non-psychiatric clinical settings such as primary care or general medical out-patients. It assesses the respondent’s current state and asks if that differs from his or her usual state. It is therefore sensitive to short-term psychiatric disorders but not to long-standing attributes of the respondent.

Data revealed that there were 56 female (74.7%) and 19 male (25.3%) patients with 36 (48%) more than 79 years of age. Patient ages ranged from 59 to 94 years, mean 77.6 years, S.D. 8.3. Thirty-six (48%) patients were of African descent, 13 (17.3%) of East Indian descent and 26 (34.6%) other ethnicities. Thirty (40%) were married, 32 (42.7%) widowed, 6 (8%) were single

and 5 (6.7%) divorced. Duration of symptoms of dementia was 0.08 to 14 years, mean 4.3 years, S.D. 3.5.

Most caregivers were females 61 (81.3%) and 48 (64%). Caregiver ages ranged from 27 to 86 years, mean 57.3, s.d. 15.2. The majority of the caregivers were offspring 32 (42.7%) and spouses 18 (24%). Forty-one (54.7%) caregivers were married and 35 (46.7%) had secondary school education.

The ZBI scores ranged from 0 to 63 with a mean of 22.7, S.D.14.7. and 41 (55%) overall had some degree of burden. According to the Zarit Buren Interview scores, 45% experienced little or no burden, 43% experienced mild to moderate burden, 11% moderate to severe burden and 1% severe burden. The GHQ Scores were >47 in 49.3% of caregivers (p=0.01).

The preponderance of females with dementia in this study is significant and in keeping with international studies.<sup>26-28</sup> Persons who were not of East Indian or African descent were described as belonging to a minority ethnic group. It is therefore surprising that in our study there were only 13 (17.3%) persons of East Indian descent with dementia since, according to the 2011 Census, persons of East Indian descent comprised 35.4%, African descent 34.2%, mixed persons comprised 22.8%, and other ethnic groups 1.4%.<sup>2</sup> Whether this is due to lower numbers of East Indian patients with dementia is a finding that requires exploration in future studies.

Caregiver burden was significantly associated with the patient being male (p=0.03) and the patient belonging to a minority ethnic group (p=0.07). Our study answers the question ‘who are the caregivers?’. Akin to other reports<sup>29,30</sup> we too have found that over 80% of caregivers are women, more specifically middle-aged women. It is notable that the majority of these women are adult children and spouses. Though we have found that the degree of burden with respect to the Zarit Burden Interview score did not differ from other caregivers, this is a group that is at increased risk for stress-related medical conditions since they form the majority of the caregivers. Although other studies report higher caregiver burden in female caregivers,<sup>31</sup> there was no correlation between gender of the caregiver and burden in the present study.

Our study found no significant correlation between relationship of the caregiver to the patient, cohabiting status of the caregiver, marital status of the caregiver, educational level of the caregiver and occupation of the caregiver.

The GHQ Scores, a measure of psychiatric morbidity, were >47 in 49.3% of caregivers. Higher caregiver

burden scores using the ZBI were associated with higher caregiver GHQ scores, a finding that supports previous studies.<sup>32</sup> Research has shown that caregivers of demented patients are nearly twice as likely to have symptoms of depression compared with caregivers of non-demented people. As such, caregivers should be advised to protect their personal time, watch out for symptoms of depression such as crying more, sleeping/eating more or less than usual and lack of interest in usual activities.

Our study found that 45% of the caregivers experienced little or no burden. This might reflect the easy acceptance of dementia for the elderly in the Trinidadian population where taking part of the elderly is a normal intergenerational experience. In Trinidad, it is not culturally usual to institutionalize aged family members (demented or otherwise) and the elderly are commonly a part of normal living in many households. More than half of the caregivers (55%) had moderate to severe burden.

Another issue that this study hints at is the impact of this unpaid care giving on the financial health of these individuals who, in their middle age, have other responsibilities including taking care of their own families. This is an area that would need follow-up studies. This is especially important since the average duration of dementia in our study was 4.4 years.

In the absence of state and private agencies to support the elderly, the familial care networks have been and continue to be the main source of support for seniors in Trinidad and Tobago.<sup>33</sup> Our findings underscore the global impact of caring for a person with dementia and support the need for caregiver support, education, training and access to medical care.

## THE PREVALENCE AND ECONOMIC COST OF DEMENTIA IN TRINIDAD AND TOBAGO

In 2012, we launched the Prevalence of Dementia and its Socio-economic Burden study in Trinidad and Tobago.

The project is a collaboration between the Dementia Awareness Research of Trinidad & Tobago (DARTT), Faculty of Medical Science and the Centre for Health Economics, Faculty of Social Sciences, The University of the West Indies.

The fundamental purpose of this project is to determine the prevalence of dementia in persons aged 60 and above in all municipalities in Trinidad and Tobago. This study will also determine the associated cost and implications for the family and caregivers, health care system and economy of Trinidad and Tobago.

The prevalence study will use validated 10/66 interview protocols<sup>34,35</sup> together with a socioeconomic ques-

tionnaire generated by the Center of Health Economics unit of The University of the West Indies.

The protocols of the key research instrument, the 10/66, have successfully established the prevalence of dementia in a number of countries including Cuba, Mexico, Peru, Venezuela, the Dominican Republic, India and China.<sup>35,36</sup> With the use of an extended 10/66 protocol and collaboration with Professor Robert Stewart (Institute of Psychiatry, King's College London) a founding member of the 10/66 research group, it is certain that our result can be compared with data from other countries. This would have a significant effect on the interpretation of results as to future trends and impact of dementia in our local setting.

Dementia will be diagnosed using an abbreviated and recently validated version of the 10/66 assessment schedule.<sup>35</sup> The component measures will consist of the Community Screening Instrument for Dementia (CSI-D), the CERAD 10-word list recall task, and the EURO-D depression scale.

Standard practice in 10/66 surveys to date has been to recruit 2000 participants aged 65 years and over per site.<sup>34,35</sup>

Our survey in Trinidad and Tobago will improve on the usual 10/66 design in two ways:

1. It will be the first 10/66-style survey of a national population (rather than a geographic catchment);
2. It will be the first such survey to adopt age-stratified sampling. The latter approach is feasible in Trinidad and Tobago because of the recent national census which provides the opportunity to sample within age ranges (something not possible for most countries) and is particularly valuable for a disorder such as dementia whose prevalence increases exponentially with age (approximately doubling with every 5-year increase in age after 65).

The proposed sample will be recruited in the following strata: 500 participants aged 60-69 years, 500 aged 70-79, 500 aged 80-89, 500 aged 90+, randomly sampled throughout all municipalities in Trinidad and Tobago.

To ensure that our door-to-door 10/66 surveys are conducted in a similar manner as those performed in the other countries, Professor Robert Stewart, our International consultant, conducted a training workshop for the 30 selected field workers.

The field work has now been completed and the data is being analyzed so that determination of the prevalence of dementia and its socioeconomic burden in Trinidad is imminent.

The impacts of this study are as follows:

1. Firstly, this study is the first of its kind in Trinidad and Tobago and will allow our policymakers to comprehend both the current prevalence and impact of dementia.

2. Impact of the socioeconomic findings from our study. It is anticipated that the findings of this study will build awareness of the full cost of dementia (including some cost elements that may not have been as obvious to those not directly impacted by dementia). This study will detail the needs of the individual and households affected by dementia with a view to enhancing the welfare and wellbeing of such individuals and households

3. To raise public awareness about dementia which in turn should: reduce stigmas surrounding the disorder, encourage early diagnosis, help family and caregivers cope with the disorder, lead to the adoption of healthier life styles which could postpone the onset of dementia.

4. One of the anticipated impacts of our study is that policy makers will make dementia a national priority by adopting and implementing a National Dementia Plan.

**Conclusion.** The research presented in the this review is the result of the efforts of three staff members of the Faculty of Medical Sciences at the University of the West Indies who pooled their expertise to advance knowledge about dementia. It has been indeed a rewarding jour-

ney and the fruits of our research are beginning to be revealed. For one, we are also very pleased to have been asked to be members of a committee that will produce the National Dementia plan for Trinidad and Tobago. Secondly, we consider that through our various types of outreach we have been increasing dementia awareness in Trinidad and Tobago.

It is our goal, as we continue with our research, that it makes a difference for those affected by the disorder either directly or indirectly, that it allows policy makers to give a high priority to dementia research, and that systems will be put into place to decrease caregiver burden. All of these should indeed mitigate the dementia tsunami in Trinidad and Tobago.

**Acknowledgments.** We would like to express our appreciation to the Alzheimer's Association of Trinidad and Tobago and all persons who volunteered to participate in this research including patients, caregivers, members of the Senior Achievers and Golden Years. We would also like to extend our appreciation to all of our research assistants who carried out much of the work presented in this review. Funding was provided by several grants from the University of the West Indies Campus Publication Research fund and a generous grant from the Government of Trinidad and Tobago.

## REFERENCES

1. Republic of Trinidad and Tobago Ministry of Planning and the Economy - Central Statistical Office. 2011 population and housing census preliminary count.pdf
2. Miller GJ, Maude GH, Beckles GL. Incidence of hypertension and non-insulin dependent diabetes mellitus and associated risk factors in a rapidly developing Caribbean community: the St James survey, Trinidad. *J Epidemiol Community Health* 1996;50:497-550.
3. Hutchinson G, Hickling F. Epidemiology of mental illness. In: Hickling FW, Sorel E, editors. *Images of psychiatry: The Caribbean*, Kingston Stephenson Litho Press; 2005:123-136.
4. Eldemire-Shearer N, Gibson R. Geriatric Psychiatry. In: Hickling FW, Sorel E, editors. *Images of Psychiatry: The Caribbean*, Kingston Stephenson Litho Press; 2005:234-240.
5. The Latest World Health Organization report 'Dementia: a public health priority'; 2012.
6. Folstein M, Folstein S, McHugh P. Mini mental state: a practical method for grading the cognitive state of patients for the clinician. *J Psychiatr Res* 1975;12:189-198.
7. Davis G, Baboolal N, Nayak S, McRae A. Sialic acid, homocysteine and CRP: Potential markers for dementia. *Neurosci Lett* 2009;465:282-284
8. Seshadri S, Beiser A, Selhub J, et al. Plasma homocysteine as a risk factor for dementia and Alzheimer's disease. *N Engl J Med* 2002;346:476-483.
9. Vogel T, Dali-Youcef N, Kaitenbach G, Andrès E. Homocysteine, vitamin B12, folate and cognitive functions: a systematic and critical review of the literature. *Int J Clin Pract* 2009;63:1061-1067.
10. Kuo HK, Yen CJ, Chang CH, Kuo CK, Chen JH, Sorond F. Relation of C-reactive protein to stroke, cognitive disorders, and depression in the general population: systematic review and meta-analysis. *Lancet Neurol* 2005;4:371-380.
11. Pickup JC, Mattcock MB, Cook MA, Chusney GD, Burt D, Fitzgerald AP. Serum sialic acid concentration and coronary heart disease in NIDDM. *Diabetes Care* 1995;18:1100-1103
12. Hangloo B, Kaul I, Zargar H. Serum sialic acid levels in healthy individuals. *J Postgrad Med* 1990; 36:140-142.
13. Wang SS, Rymer DL, Good TA. Reduction in cholesterol and sialic acid content protects cells from the toxic effects of  $\beta$ -amyloid peptides. *J Biol Chem* 2001; 276:42027-42030.
14. McRae A, Ling EA. Cerebrospinal fluid and serum anti microglial antibodies: prospects for early diagnosis of Alzheimer's disease. *Expert Rev Neurother* 2003;3:247-257.
15. McGeer PL, McGeer EG. The inflammatory response system of brain: implications for therapy of Alzheimer and other neurodegenerative diseases. *Brain Res Brain Res Rev* 1995;21:195-218.
16. Consensus report of the Working Group on: "Molecular and Biochemical Markers of Alzheimer's Disease". The Ronald and Nancy Reagan Research Institute of the Alzheimer's Association and the National Institute on Aging Working Group. *Neurobiol Aging* 1998; 19:109-116.
17. McRae A, Martins RN, Fonte J, Kraftsik R, Hirt L, Miklossy J. Cerebrospinal fluid antimicroglial antibodies in Alzheimer disease: a putative marker of an ongoing inflammatory process. *Exp Gerontol* 2007;42:355-363.
18. Davis GK, Baboolal NS, Seales D, Ramchandani J, McKell S, McRae A. Potential biomarkers for dementia in Trinidad and Tobago. *Neurosci Lett* 2007; 424: 27-30.
19. Jaikaran ET, Clark A. Islet amyloid and type 2 diabetes: from molecular misfolding to islet pathophysiology. *Biochim Biophys Acta* 2001;1537:179-203.
20. Yaffe K, Blackwell T, Kanaya AM, Davidowitz N, Barrett-Connor E, Krueger K. Diabetes, impaired fasting glucose, and development of cognitive impairment in older women. *Neurology* 2004;63:658-663.
21. Prince M, Prina M, Guerchet M. *Alzheimer's Disease International*.

- World Alzheimer Report 2013 Journey of Caring - an analysis of long-term care for dementia . Alzheimer's Disease International. <http://www.alz.co.uk/research/WorldAlzheimerReport2013.pdf>
22. Richardson TJ, Lee SJ, Berg-Weger M, Grossberg GT. Caregiver health: health of caregivers of Alzheimer's and other dementia patients *Curr Psychiatry Rep* 2013;15:367.
  23. Karlikaya G, Yukse G, Varlibas F, Tireli H. Caregiver Burden In Dementia: A Study In The Turkish Population. *Int J Neurol* 2004;4(2).
  24. Zarit SH, Orr NK, Zarit JM, editors *The hidden victims of Alzheimer's disease: Families under stress*. New York: New York University Press; 1985.
  25. *Diagnostic and Statistical Manual of Mental Disorders, 4th Edition, Text Revision (DSM-IV-TR)* BY American Psychiatric Association; 2000.
  26. Ott A, Breteler MM, van Harskamp F , Stijnen T, Hofman A. Incidence and risk of dementia. The Rotterdam Study. *Am J Epidemiol* 1998; 147: 574-580.
  27. Schmidt R, Kienbacher E, Benke T, et al. Sex differences in Alzheimer's disease. *Neuropsychiatr* 2008;22:1-15.
  28. Plassman BL, Langa KM, Fisher GG, et al . Prevalence of dementia in the United States: the aging, demographics, and memory study . *Neuroepidemiology* 2007; 29:125-132
  29. Alzheimer's Association and National Alliance for Caregiving. *Families care: Alzheimer's Caregiving in the United States*; 2004. [https://www.alz.org/national/documents/report\\_familiescare.pdf](https://www.alz.org/national/documents/report_familiescare.pdf)
  30. MetLife Mature Market Institute. *The MetLife study of Alzheimer's Disease: the Caregiving Experience*; 2006. <https://www.metlife.com/assets/cao/mmi/publications/studies/mmi-alzheimers-disease-caregiving-experience-study.pdf>
  31. Prince M, Brodaty H, Uwakwe R, et al Strain and its correlates among carers of people with dementia in low-income and middle-income countries. A 10/66 Dementia Research Group population-based survey. *Int J Geriatr Psychiatry*. 2012 27:670-682.
  32. Shaji KS, George RK, Prince MJ, Jacob KS. Behavioral symptoms and caregiver burden in dementia. *Indian J Psychiatry* 2009;51:45-49.
  33. National report Republic of Trinidad and Tobago at the third Regional Intergovernmental Conference on Ageing in Costa Rica. Ministry of the People and Social Development Division of Ageing; 2012. <http://www.cepal.org/celade/noticias/paginas/9/46849/TrinidadTabago.pdf>
  34. Prince M. Methodological issues for population-based research into dementia in developing countries. A position paper from the 10/66 Dementia Research Group. *Int J Geriatr Psychiatry* 2000;15:21-30.
  35. Prince M, Acosta D, Chiu H, Scazufca M, Varghese M; 10/66 Dementia Research Group. Dementia diagnosis in developing countries: A cross-cultural validation study. *Lancet* 2003; 361: 909-917.
  36. Prince M, Ferri CP, Acosta D, et al. The protocols for the 10/66 dementia research group population-based research programme. *BMC Pub Health* 2007;7:165.



# IN SEARCH OF ALZHEIMER'S

SIGNIFICANT RESEARCH AT UWI COULD  
CONTRIBUTE TO EARLY DETECTION OF  
THE DISORDER AND PROMOTE GREATER  
UNDERSTANDING OF THE DISEASE

**I have profound admiration** for the 'round-the-clock care shown by my friends for parents who have been transformed by this disease. I've listened to their stories of sadness and frustration. But how do you respond to accounts of a mother who no longer remembers the names of her children or a father who gets lost on the way home? These are the details of a life derailed by Alzheimer's, of a once-fiercely-independent parent who is sliding into a world of silence and slowness.

Although Alzheimer's disease was discovered in 1906, it is only over the past two decades that knowledge about the disease process has gained momentum. This is as a result of the development of novel investigative techniques combined with the work of dedicated researchers.

In 2003, three doctors at The University of the West Indies Faculty of Medical Sciences combined their expertise to make great strides in Alzheimer's and Dementia research in Trinidad and Tobago. **Dr. Nalleen Baboolal, Dr. Gershwin Davis and Professor Amanda McRae** began developing a three tiered project that could yield breakthrough results by examining not only the epidemiology of Dementia, but the associated risk factors; and ultimately establishing **biomarkers** for the disease.

There is no cure for Alzheimer's, a brain disease that has affected millions around the world and placed tremendous pressure on caregivers and families. Although the greatest risk factor is increasing age, and most people with the disease are 65 years and older according to the Alzheimer's Association, it isn't just a disease of old age. In fact up to five percent of people with the disease have early onset, which means that symptoms may appear in the forties and fifties and get progressively worse. While in the early stages memory loss is mild, in the later stages the individual may lose the ability to communicate with others and the activities of daily living become all but impossible.

# IN SEARCH OF ALZHEIMER'S

Alzheimer's is the sixth leading cause of the death in the USA and those affected may live on average eight years after symptoms become noticeable to others, but the survival rate can range from four to twenty years. Worldwide the focus is on treatment, finding better ways to prevent the disease from developing and delaying its onset. Treatment is available and research, like the work being done at UWI and other institutions, provide hope.

Although there have been challenges in funding, the UWI team has pushed through the difficulties and their work has generated international interest and collaboration, alongside a slew of landmark discoveries.

One key facet of the project of these esteemed scientists is revolutionary: the potential for developing a serum screening biomarker for the disease that could introduce a paradigm shift in the way we approach the health care maintenance of the elderly. This is due to the fact that a serum marker would provide a universal means to differentiate Alzheimer's Disease (AD) from other dementias, as well as establish early detection of the disorder.

But what is a biomarker? A biomarker is a substance such as an antibody or protein which is usually present in either the cerebrospinal fluid or blood.

The team explained in detail that according to the criteria of the Consensus Report of the Working Group on Molecular and Biochemical Markers of AD, an ideal biomarker should: be able to detect a fundamental feature of AD neuropathology; and be validated in

neuropathologically confirmed AD cases; be precise (able to detect AD early in its course and distinguish it from other dementias); reliable; non-invasive; simple to perform; and inexpensive.

For the UWI researchers, the most exciting milestone occurred in 2008, after conducting a workshop entitled "Biomarkers for Dementia. Is there a role?" at the American Association of Clinical Chemistry Conference in Washington DC.

"This attracted the attention of a major UK based diagnostic company. Subsequently collaboration developed between this company and UWI to further the development of a diagnostic biomarker for Alzheimer's disease," Dr. Davis, a Senior Lecturer in Chemical Pathology at the Faculty of Medical Sciences explained. He has been working alongside Dr. Amanda McRae, Professor of Human Anatomy and Dr. Nelleen Baboolal, a Senior Lecturer in Psychiatry at UWI.

But this was not the only success for the team, the research also helped in initiating investigations about caregiver burden, the extent of Dementia in nursing homes versus senior centres and in completing preliminary research on cognitive impairment in diabetics.

"This is a collaborative effort not on a specific project but on the theme Alzheimer disease and Dementia and Mild Cognitive Impairment (MCI). To that end we established and incorporated Dementia Awareness and Research of Trinidad and Tobago (DARTT), a non-profit company in order to better pursue

our research goals and to extend the awareness of Dementia to the general population," Dr Davis added.

"This collaboration has benefited from the expertise of Professor S. Teelucksingh of The University of the West Indies and Dr. R. Stewart of the Institute of Psychiatry, King's College, London. Our collaborative efforts have generated several publications, book chapters, workshops and conference presentations at international conferences including the International Conference on Alzheimer Disease, Vas Cog, American Association of Clinical Chemistry Conference and Caribbean Health Research Conference."

Education about the disease is integral to effective health care and over the years Drs. McRae, Davis and Baboolal through the DARTT foundation, were able to heighten public awareness of Dementia and help to reduce the associated stigma by focusing on the caregivers and contributing to the literature.

Over the years, funding has been the greatest challenge, and this combined with a hectic teaching schedule have been key factors affecting the progression of the work.

"It is important to note that medical school teaching in the clinical years is year round unlike other areas of study at the UWI. Consultant staff also has hospital on-call 24-hr duties. This combination makes for a tight schedule which can reduce intellectual time spent on research planning and execution," Dr. Davis explained.

“Another area of challenge is the lack of expertise and local data in some of the emerging cutting edge areas of research. This implies that staff interested in advancing knowledge in these priority areas must first build their own research capacity which includes basic training of staff and students as well as production of pilot data before funding of any significance can be applied for,” he added, underscoring an issue that has had a profound impact on research in the region.

Alongside the challenges, I also asked the team if they saw any benefits from being part of a regional University with decades of expertise in medicine; their answer was one of the advantages of pooling resources to capitalize on funding opportunities and multicentre research among collaborators from different territories and institutions.

“We should be able to do multicentre research. We are not aware that it is as common as it should be. Multicentre research with colleagues as collaborators from different territories and UWI campuses would give breadth and depth to the impact of the results of our research. It may also allow us to write for larger grants from international institutions. We also have the possibility of doing research on different ethnic groups and making a comparison in people living generally under the same circumstances. It may be easier for us to do longitudinal studies [on] our population since we are less likely to suffer the effects of migration when compared to some places in Europe and the United States.”

As for the suggestions to students who may wish to enter this field of research? The doctors advised that “hard work and dedication to the cause are essential for success”.



Alzheimer’s is the sixth leading cause of the death in the USA and those affected may live on average eight years after symptoms become noticeable to others, but the survival rate can range from four to twenty years.

It is a fact that Alzheimer’s and Dementia are diseases of an aging population and that the incidence doubles for every decade above 60 years. Ultimately, the team noted that as our population ages the burden of this chronic disease would have a more significant impact on the family and in turn the health care budget. In fact, they explained that “risk factor elucidation and biomarker studies would assist physicians in the management of this patient group.” And this is why this research is so important. This is why gaining a better hold on what this disease is all about and monitoring its progression are so fundamental to our future. Research on the prevalence of the disease could help Governments, health care institutions and indeed our friends and families plan for the future. Indeed it can help us recognize and plan for a change within ourselves. ■

*Anna Walcott Hardy*



# IN SEARCH OF ALZHEIMER'S

**GERSHWIN DAVIS**, a Senior Lecturer in Chemical Pathology at the Faculty of Medical Sciences at The University of the West Indies (UWI) Eric Williams Medical Sciences Complex in Trinidad, received his medical degree from The UWI, Mona Campus and a PhD in Chemistry at the St Augustine Campus. A Fulbright Fellow at the University of Minnesota at Hennepin County Medical Centre U.S.A. and at The Stanford Jackson Fellow at The Hospital for Sick Children in Toronto, he was a senior house officer at the Port of Spain General Hospital prior to joining UWI. He is currently consultant Chemical Pathologist at the Scarborough Regional Hospital Tobago. Dr Davis' research interest is in biomarkers in Alzheimer's disease and he is one of the directors and founding members of the Dementia Awareness and Research group, Trinidad and Tobago (DARTT). He is author or co-author of more than 60 peer-reviewed journal articles, abstracts, book chapters and invited papers. He has been an active member of the American Association for Clinical Chemistry since 1999 and is a diplomat of the American Board of Clinical Chemistry and a Fellow of both the American Academy of Clinical Biochemistry and The Canadian Academy of Clinical Biochemistry. He is also a Medical Review officer with the American Association of Medical Review officers. ■



**AMANDA McRAE** is presently Professor of Human Anatomy at the Faculty of Medical Sciences at the UWI St Augustine campus, Eric Williams Medical Sciences Complex in Trinidad. She received her BSc in chemistry from the University of Alabama in Birmingham and postgraduate degree (field neurobiology) from the University of Claude Bernard Lyon, France. Prior to joining The UWI she was an INSERM scientist in Montpellier and Bordeaux, France and a medical research council fellow in Sweden. She also received scholarships to perform research at the Institute of Gerontology in Tokyo, Japan and at the Hadassah Medical Center in Jerusalem, Israel. Her research interests are in biomarkers for Alzheimer's disease, the influence of diet on brain inflammation, neuroprotective agents, drug delivery systems for Parkinson's disease and the prevalence and risk factors associated with dementia in Trinidad and Tobago. She is author and co

-author of more than 100 peer-reviewed journal articles, abstracts, book chapters and invited papers. She was a recipient of a stipend from Sandoz Gerontology for Alzheimer's disease research performed in collaboration with Dr. E.A. at the National University of Singapore and in 1996 received the medal of honor from Svenska Parkinsonförbundets for the development of the microsphere technology as a treatment for Parkinson's disease. She has two patents. She has served as a reviewer for Alzheimer grants and numerous international journals. She is one of the directors and founding members of the Dementia Awareness and Research group Trinidad and Tobago (DARTT). ■



**NELLEEN BABOOLAL** is presently Senior Lecturer in Psychiatry at the Faculty of Medical Sciences, St. Augustine Campus and a Consultant Psychiatrist at the Eric Williams Medical Sciences Complex. A medical practitioner for just under thirty years, Dr. Baboolal received her undergraduate and postgraduate degrees, M.B.B.S., Dip. Psych., D.M. Psych., from The UWI. She is a member of the Psychiatric Tribunal of Trinidad and Tobago and was the recipient of a Fellowship in Drug Addiction at the University of Toronto. She is the recipient of grants funded by the Government of Trinidad and Tobago Research Development Fund and the Campus Research and Publication Fund. Her research interests include epidemiology of dementia and Alzheimer's disease, biomarkers in Alzheimer's disease and other dementias, depression and cognitive impairment in diabetes, medical student education, mental health after disasters and emotional intelligence in medical personnel. She has authored and co-authored more than 45 peer-reviewed journal articles, abstracts, book chapters and invited papers and presented research papers locally and internationally. Dr. Baboolal is the coordinator of the postgraduate Doctor of Medicine (D.M.) Psychiatry programme at The University of the West Indies St. Augustine Campus. She is one of the directors and founding members of the Dementia Awareness and Research group Trinidad and Tobago (DARTT). She has done collaborative research with the Institute of Psychiatry, King's College, London;



Dr. Nelleen Baboolal

Department of Clinical Medical Sciences, UWI; Department of Physics, UWI, and the Division of Ageing, Ministry of Social Development. She is an International member of the American Psychiatric Association, a member of the Medical Protection Society and has full Registration with the General Medical Council, U.K. She started a Memory Clinic at the Eric Williams Sciences Complex in 2003. ■

**THE DEMENTIA AWARENESS AND RESEARCH GROUP TRINIDAD AND TOBAGO (DARTT)** is a voluntary non-profit company which aims to educate the population, promote brain health, diagnose afflicted persons, support patients their families and caregivers and conduct research on Alzheimer's disease and other dementias. ■

# IN SEARCH OF ALZHEIMER'S

## SELECTED PUBLICATIONS

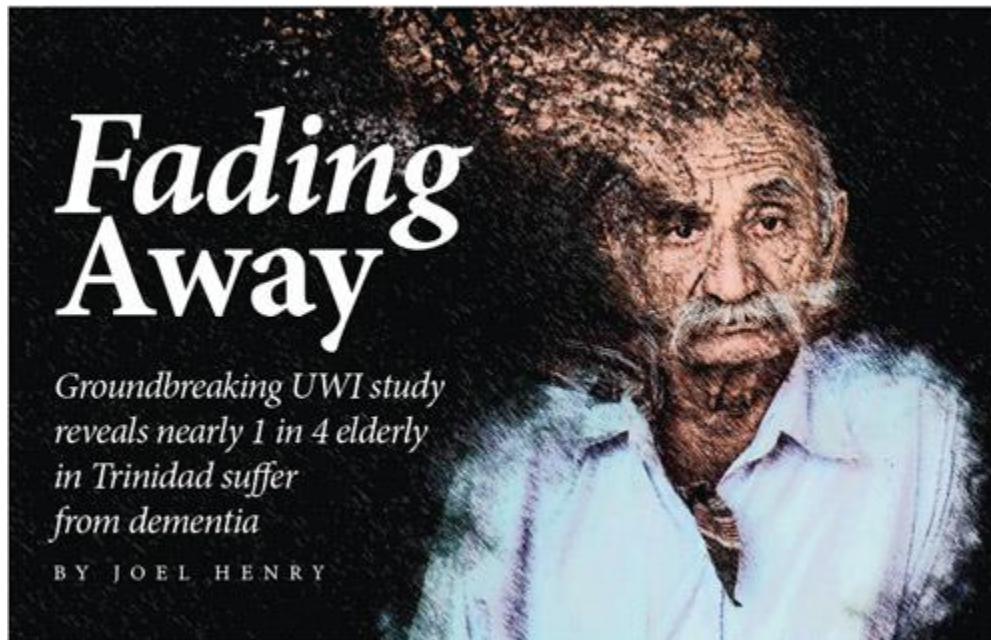
1. Baboolal, N., Stewart R., Davis, G., Mc Rae. A. **Prevalence of dementia in persons attending Social Welfare Services in Trinidad and Tobago: preliminary findings.** *West Indian Med J* 2010; 59 (Suppl. 2): 47.
2. Baboolal, N., Davis. G., Stewart, R., Ramesar, J., McRae A. **Pioneering study on caregiver burden and dementia in the southern Caribbean.** *Alzheimer's & Dementia: The Journal of the Alzheimer's Association* July 2010 (Vol. 6, Issue 4, Supplement, Page S335)
3. Baboolal, N., Davis, G., Mc Rae. A. **Assessment of caregiver burden in patients with dementia.** *West Indian Med J.* 2009
4. Davis, G., Baboolal, N. McRae, A. **Biomarkers for dementia: Putting the focus on microglia.** *Clinical Laboratory International.* 2010
5. Davis G, Baboolal N, Nayak S, Mc Rae A. **Sialic acid, homocysteine and CRP: potential markers for dementia.** *Neurosci Lett.* 2009; 465: 282-4.
6. Davis, G., Baboolal, N., Skinner, T., Nayak S., **Homocysteine and inflammatory markers in dementia and the elderly.** *Clin Chem, Vol. 54, No 6, Supplement* 2008
7. Davis, G., Mc Rae, A, Baboolal N. **Biomarkers in dementia.** Booklet American Association Clin Chem 2008
8. Davis, G., Baboolal, N., Morren, J., Skinner, T., Mc Rae. A. **Prevalence of cognitive impairment and dementia risk among diabetic patients in the County of St. George Central, Trinidad.** *West Indian Med J.* 2008; 57 (Suppl. 2): 47
9. McRae, A., Davis. G., Baboolal N. and Morren. J. **Alzheimer's Disease in the Middle-Aged. Chapter 12 pp Biomarkers in Alzheimer's disease** Editors: Hyun Sil Jeong. Year of Publication: 2008 Cover: Hardcover. ISBN: 978-1-60456-480-8.
10. Davis, G., Baboolal, N., Seales, D., Ramchandani, J., McKell, S., Mc Rae., A. **Potential biomarkers for dementia in Trinidad and Tobago.** *Neuroscience Letters,* 2007; 424, 27-30.
11. Baboolal N, Davis G, Ramachandii J, McRae A. **Alzheimer's disease: NEW ADVANCES. Collection of Selected Articles of Papers Presented at the 10th International Conference on Alzheimer's Disease and Related Disorders Risk factors and biomarkers in Alzheimer's disease in Trinidad and Tobago.** pp 45-49. Date: July 16-20, 2006 *Editor(s):* Iqbal K., Winblad B., Avila J. *Year of Publication:* 2007 *Cover:* Paperback \* *Pages:* 698 *Ref. code:* 20060716 *ISBN:* 978-88-7587-322-6.
12. Davis G, Baboolal N, Mc Rae A, Ramchandani J **Total Homocysteine and anti Microglia Antibodies in Patients with Confirmed Alzheimer's Disease and Alzheimer's Disease with Vascular Dementia (Mixed Dementia).** *West Indian Med J.* 2006;(Suppl 2):68.
13. Davis GK; Baboolal N; Skinner T; Nayak S; McRae A. **Homocysteine and inflammatory markers in dementia and the elderly.** *Clin Chem* 2008:S6A40
14. Baboolal NS; Davis GK; Seales D; Ramchandani J; McKell S; McRae A. **Dementia and the elderly: A comparative study.** *West Indian Med J* 2007; 56 (Suppl. 1): 58.
15. Davis GK; Seales D; Baboolal NS; McRae A; Seemungal TAR. **A reference interval study for C-reactive protein.** *West Indian Med J.* 2007; 56 (Suppl. 1): 63.
16. McRae A; Baboolal N; Davis G; Ramchandani J. **Risk factors and biomarkers in Alzheimer's disease in Trinidad and Tobago.** *Alzheimer's & Dementia: The Journal of the Alzheimer's Association.* 2006; Vol. 2, Issue 3 (Supplement), S397
17. Davis GK; Baboolal NS; Mc Rae A; Ramchandani J. **Total Homocysteine and anti Microglia Antibodies in Patients with Confirmed Alzheimer's Disease and Alzheimer's Disease with Vascular Dementia (Mixed Dementia).** *West Indian Med J* 2006;(Suppl 2):68.

February 03 2019



HEALTH AND WELLNESS

## *Dementia Research*



Many of us have the experience of an elderly relation afflicted with dementia. It takes a powerful toll on the sufferer and those close to them. We accept it as a consequence of ageing. But dementia is not natural or normal. It's an illness, one that is having an abnormally heavy impact on Trinidad and Tobago.

A prevalence study by researchers at UWI's St Augustine Campus

has revealed that some 23.5% (nearly one in four) Trinidadians over the age of 70 have dementia. This figure is almost three times the prevalence in other countries. At age 85 and older it rises to 47%. The comprehensive study had over 1,850 active participants chosen randomly from 120 districts in Trinidad.

"Dementia is a major public health concern and is a global epidemic," says Dr Nelleen Baboolal, Senior Lecturer in Psychiatry and Head, Department of Clinical Medical Sciences at UWI St Augustine's Faculty of Medical Sciences (FMS). Dr Baboolal is a member of the research team.

The UWI study, titled "The Prevalence and Economic Cost of Dementia Project in Trinidad and Tobago", was carried out in collaboration with the University's Health Economics Unit. The project was co-funded by the UWI-Trinidad and Tobago Research and Development Impact (RDI) Fund and the Ministry of Health.

The research team attributes the unusually high number of dementia sufferers to two main factors – the country's ageing population and, more importantly, the high prevalence of vascular risk factors including diabetes mellitus, hypertension, high cholesterol and obesity.

“The risk factors for diabetes and cardiovascular diseases such as hypertension are also the risk factors for dementia,” says Dr Gershwin Davis, Senior Lecturer in Chemical Pathology, Head of Department of Paraclinical Sciences (Laboratory Medicine) at FMS and member of the research team.

Dementia is a neurocognitive disease that affects memory, thinking, behaviour and the ability to perform everyday activities. Globally, Alzheimer's disease is the most common form of dementia, representing about 65% of the afflicted. Vascular dementia (problems with blood supply to the brain) is the second most common cause. Other causes include conditions such as vitamin B12 deficiency, HIV and AIDS, Parkinson's disease, tumors and head trauma resulting from activities such as boxing.



Covered in UWI Today in 2014 : ([https://sta.uwi.edu/uwitoday/archive/august\\_2014/article11.asp](https://sta.uwi.edu/uwitoday/archive/august_2014/article11.asp))

The study originated from the work of Dr Baboolal, Dr Gershwin Davis and Professor Amanda McRae, Professor of Human Anatomy at FMS (now retired), who have been collaborating on Alzheimer's and dementia research since 2003.

It followed the methodology of the 10/66 Dementia Research Group, a UK-based collective of researchers that has developed measurement tools for dementia prevalence that are currently being used in over 20 countries. Professor Robert Stewart, a founding member of the 10/66 Group, was also a co-author and consultant on the UWI study.

Apart from the prevalence of dementia in Trinidad, the study also looked at the cost, material and otherwise, to the society. Dementia has a huge socioeconomic impact. The diagnosis and treatment for dementia is also extremely costly.

The prevalence study was completed in 2015 and since then the team has been analysing the data and sharing their findings. The results have been published in several widely recognised international journals such as the British Medical Journal and the Oxford Journal of Public Health. Now that the results have been verified the next step is using the study to address the issue.

Dr Davis says, “The research could give impetus to a thrust as a matter of policy to create a dementia friendly society”.

In 2017, the UWI research team met with Health Minister Terrence Deyalsingh. The main objective of the meeting was to ask the Minister to request that Cabinet declare dementia a “chronic disease”. This designation would open up dementia-related activities to new avenues of international funding, a major step in creating policy, advocacy and public awareness, as well as further research.

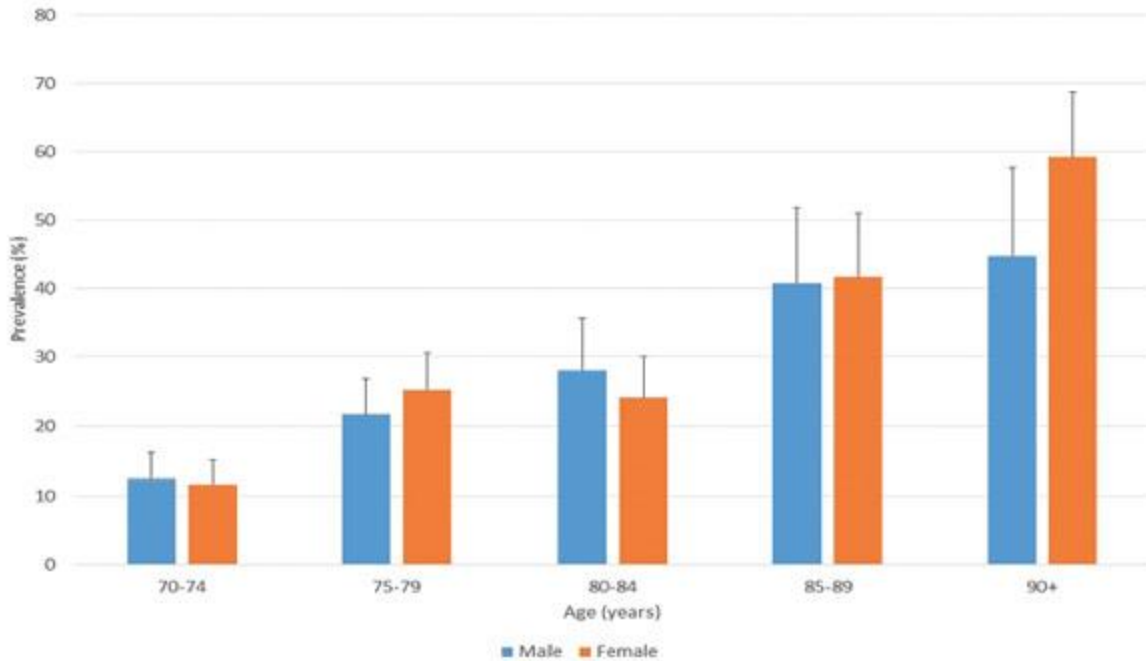


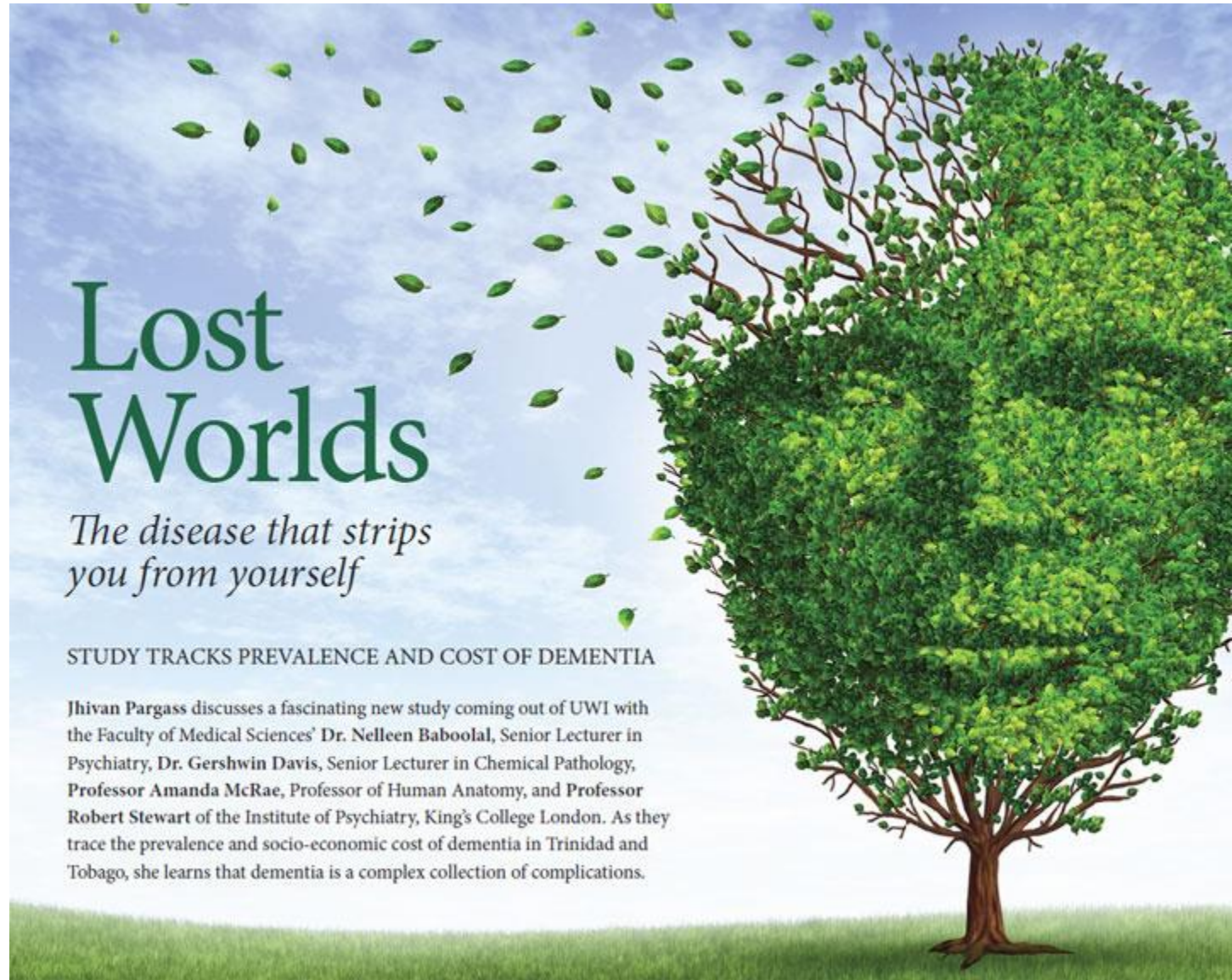
Figure 1: Dementia prevalence (%) by age and gender (with upper 95% CI).

Dr Baboolal says, “We need more research, more training of caregivers and more advocacy. Dementia is a priority in Trinidad and Tobago and we need to develop a national dementia plan to ensure that health and social services are adequately structured and funded to provide high-quality care and support to people throughout the dementia journey. The policymakers should initiate national debates regarding the future of long-term care, with all stakeholders and an informed public. I am hoping that we can come together and work to improve the quality of services for persons living with dementia”.

# UWI TODAY

THE UNIVERSITY OF THE WEST INDIES · ST. AUGUSTINE CAMPUS

August 2014



## Lost Worlds

*The disease that strips you from yourself*

STUDY TRACKS PREVALENCE AND COST OF DEMENTIA

Jhivan Pargass discusses a fascinating new study coming out of UWI with the Faculty of Medical Sciences' Dr. Nelleen Baboolal, Senior Lecturer in Psychiatry, Dr. Gershwin Davis, Senior Lecturer in Chemical Pathology, Professor Amanda McRae, Professor of Human Anatomy, and Professor Robert Stewart of the Institute of Psychiatry, King's College London. As they trace the prevalence and socio-economic cost of dementia in Trinidad and Tobago, she learns that dementia is a complex collection of complications.

Jhivan Pargass discusses a fascinating new study coming out of UWI with the Faculty of Medical Sciences' Dr. Gershwin Davis, Senior Lecturer in Chemical Pathology, Professor Amanda McRae, Professor of Human Anatomy, and Professor Robert Stewart of the Institute of Psychiatry, King's College London. As they trace the prevalence and socio-economic cost of dementia in Trinidad and Tobago, she learns that dementia is a complex collection of complications.

Imagine that an elderly loved one, perhaps an aunt, started to forget the names of everyday objects or recent events. She remembers the family luncheon she attended ten years ago, but not what she had for

breakfast, or the name of your recently born baby. The changes are small; you chalk them up to old age. But, as time progresses, she is no longer able to find the right words to express herself, and is in an increasingly confused state of mind. She develops mood swings and personality changes, loses interest in what she once loved, and forgets how to conduct daily tasks. You take her for a checkup and the doctor hits you with a staggering blow: she is showing symptoms of dementia.\*

What makes dementia confusing is that it is not actually a disease, but rather a collection of symptoms that can be caused by various diseases. The leading cause is Alzheimer's disease, but dementia can also develop due to brain damage from an injury or stroke, and from other diseases such as Parkinson's and Huntington's.

What might be even more confusing is trying to find out how many people here in our little twin islands suffer from this debilitating and incurable condition, and the costs incurred by having the disorder, or having to take care of someone who does. However, that is soon to change, thanks to a project being done in collaboration with the HEU Centre for Health Economics, and spearheaded by a team of remarkable people from the Faculty of Medical Sciences, Dr. Nelleen Baboolal, Senior Lecturer in Psychiatry, Dr. Gershwin Davis, Senior Lecturer in Chemical Pathology, and Professor Amanda McRae, Professor of Human Anatomy. They are assisted by Professor Robert Stewart (Institute of Psychiatry, King's College London), who is a founding member of the 10/66 dementia research group\*.

The two-part project, titled the Prevalence and Economic Cost of Dementia Project in Trinidad and Tobago, has a fairly detailed history. It was officially launched in April 2012, but the impetus for this particular study was there long before. In 2003, the three project leads were working on a project that focused on identifying biomarkers for dementia. Most of the study cohort was comprised of patients from Dr. Baboolal's Memory Clinic, founded in the same year. As the study progressed, one question was repeatedly asked: "How prevalent is dementia in T&T?"

So whose idea was it to add another branch to the tree? Prof. McRae says with a chuckle that it was probably all three of them at the same time. They agree that their individual, yet greatly similar interests in the disease brought them all together for what Prof. McRae calls "the greatest collaboration on the face of the earth" and what Dr. Davis describes as "a fantastic merger, a perfect fit". Both insist that Dr. Baboolal was at the core of it all, given that the cause is one "dear to her heart", and the initial project began with her Memory Clinic patients. Drs Baboolal, Davis and Professor McRae have been working together for ten years and together they form the Dementia Awareness and Research Group of Trinidad and Tobago (DARTT).\*\*\*

The prevalence study explores the multidisciplinary nature and extent of dementia, as well as the cost of the illness. In essence, the study seeks to establish the prevalence of dementia and the associated risk factors amongst the elderly population as well as evaluate the economic burden of the illness on households. It only really took off in 2014, as, with any good undertaking, there were a few "teething problems". However, these setbacks were taken in stride and a pilot study in Mayaro/Rio Claro was conducted by a team of five field workers in 2012. 13 persons in the age ranges 60-69, 70-79, 80-89 and 90 and above were interviewed using the 10/66 instrument and the socio-economic questionnaire. This investigation allowed for the testing of the instruments to be used in the actual study. The feedback was very positive, which delighted the project leaders, as participants were cooperative and expressed interest.

To adequately explain why this study is so extraordinarily important, we must first understand that the population of Trinidad and Tobago is aging. Dr. Davis explains that one of the main problems with aging is a change in the disease pattern from one of viruses and communicable diseases, to chronic non-communicable diseases, e.g. Alzheimer's. With the increase in the numbers of the elderly, a predicament arises. But what is the extent of the problem? That's the question they're trying to answer, and this is really the driving force behind the study.



The results of many prevalence studies are readily available, but these originate mainly from the developed world, with few in the Caribbean. Three Hispanic-Caribbean countries, Cuba, Puerto Rico and the Dominican Republic, have done such studies, but the DARTT study is the first of its kind in Trinidad and in the English-speaking Caribbean, which gives it even more weight. Prof. Stewart explains that determining a central figure such as the prevalence of dementia in Trinidad and Tobago is critical because for the first time, it will provide the Government, and anyone else who wants to know, with a picture of how common dementia is and the socio-economic cost that comes with it. He explains that the results will also have enormous transformative implications for policy, as they will highlight the economic reasons for investing in dementia. He paraphrased Alzheimer's Disease International, according to whom if dementia care were a country, it would be the world's 18th largest economy, given that in 2010, the worldwide costs of dementia exceeded 1% of global GDP at US\$604 billion.

As mentioned, this is a two-phase project. The goal of the completed first phase was to determine where individuals in the various age bands reside, which speeds up the process for enumerators conducting the survey in the field. 2,000 persons from 120 electoral districts were selected at random in phase one, all of whom will be revisited in the second phase, which is currently in progress. All selected persons will have their cognitive function assessed using the survey instruments developed by the FMS team, the HEU and Prof. Stewart. If everything goes smoothly, data collection and results analysis should be completed around October 2014.

Of course, none of this would have been possible without funding. Very early on, the team received a grant from the Government of Trinidad and Tobago, which enabled them to do the groundwork, but it was a TT\$550,000 grant from the UWI-Trinidad and Tobago Research, Development and Impact (RDI) Fund that allowed the study to launch. However, as with all funding, the need for more persists. The size of the grant required the team to "prune" other aspects of the research to ensure that the focus would be on the core aspects: prevalence and socio-economic cost. It also means that the study is currently focused solely in Trinidad.

The project is a timely one, as dementia becomes more and more relevant worldwide, especially due to increasingly aging populations. Its relevance is often driven by the Alzheimer's Association, an organization which is able to articulate to governments the need for increased attention to the disease, and is enormously influential in pushing for more research to be done in the field. The local branch of the Alzheimer's Association is very concerned with "upping the agenda" to guarantee that research into Alzheimer's, the main cause of dementia, is a high priority. The tireless work of such organisations coupled with studies such as this, is what keeps the argument going for more treatments and better patient care.

The data that the study will provide is fundamental to our local context, as the first thing someone usually asks when discussing the importance of any disease is "how common is it?" If that basic question can't be answered, you're stuck. There's always guesswork from international studies, but no external data can supplement results obtained from a local study, and this is just what the DARTT prevalence study will supply to Trinidad, and soon, to Tobago. The team also plans to take the project even further, by following the cohort of persons with dementia to look for associated risk factors by doing blood testing and neuroradioimaging, by studying persons aged 90 and above, and by informing policy makers regarding aging. They also plan to conduct similar studies in other Caribbean islands, and, once funding becomes available, there will be follow-up studies focusing specifically on various kinds of dementia.

For now, the goal is to complete phase two have the results analysed and published. Once this is done, it will provide a more accurate picture for everyone—not just the government, but society in general, because as Prof. Stewart so rightly put it, "Dementia belongs to everyone; it is everyone's business."



**\* The Pan-American Health Organization (PAHO) defines dementia is a syndrome that affects memory, thinking, behaviour and ability to perform everyday activities. The organization estimates that the number of people living with dementia worldwide is currently estimated at 35.6 million.**

**\*\* The 10/66 Dementia Research Group is a collective of researchers carrying out population-based research into dementia, non-communicable diseases and ageing in low and middle income countries.**

**\*\*\* DARTT is a voluntary non-profit which aims to educate the population, promote brain health, diagnose afflicted persons, support patients, families, caregivers and conduct research on Alzheimer's disease. Much more information on the study and the group's other fascinating and pioneering work is available on the website: [www.dartt.org.tt](http://www.dartt.org.tt)**

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## **The greatest collaboration on earth**

The two-part project, titled the Prevalence and Economic Cost of Dementia Project in Trinidad and Tobago, has an approach unique to Trinidad and Tobago as it is the first survey of a national population, rather than a geographic catchment. The project itself has a fairly detailed history. It was officially launched in April 2012, but the impetus for this particular study was there long before. In 2003, the three leads were working on a project that focused on identifying biomarkers for dementia. Most of the study cohort was comprised of patients from Dr. Baboolal's Memory Clinic, founded in the same year. As the study progressed, one question was repeatedly asked: "How prevalent is dementia in T&T?"

## The enormous economic cost of care



Dementia is a chronic disease that can take up to around ten years to reach the end-stage, and accompanying it is a massive economic burden. For this reason, the HEU Centre for Health Economics is a partner of the study, Director Professor Karl Theodore lending his expertise to the project. The HEU describes briefly the socio-economic component of the study:

“While persons living with dementia can still have a good quality of life provided that they receive adequate care, they have unique needs which start early in the disease and evolve constantly over time, which are associated with higher costs of care compared with other long-term care users. In this context, the socio-economic component of the study explores the direct cost of medical care as well as the direct cost of formal care (paid home or care in homes) and the indirect cost of informal care (care provided by the unpaid family caregivers). It is

expected that this information will provide decision makers with the information necessary to formulate policies to effectively address the needs of those living with or affected by dementia in Trinidad and Tobago”.

Both Prof. McRae and Dr. Davis emphasise that dementia not only affects the patient, but family members as well, as they may have to relinquish their jobs, and therefore their income. People who provide this informal care often also end up damaging their own health because caring for a dementia patient can be extremely emotionally and physically demanding, especially in the later stages, and not all families can afford formal care. In thinking about caring for dementia patients, it is not always considered that a significant amount of money also goes towards the healthcare of the caregivers. The International Alzheimer’s Association reports that in 2013, due to the physical and emotional burden of caregiving, Alzheimer's and dementia caregivers had \$9.3 billion in additional healthcare costs of their own.

# Trinidad & Tobago Guardian

Wed Oct 09 2013

## Coping with dementia

By: Joanne Briggs

Audrey Karim and her mother used to quarrel a lot. They were two strong personalities who believed their way was the right way. Their disagreements were regular events, to the point it got Audrey distressed.

Until during one of their tiffs, Audrey told her mother, "Enough!" and let her have it. Although she felt this time she had the final word, there was no satisfaction in it.

It was only after that last incident she realised something was wrong.

Her mother regressed from aggressive, to belligerent, to docile.

She was diagnosed with Alzheimer's disease, a progressive, degenerative disease that attacks the brain.

In its progressive state, Audrey says her mother now has very little language skills. "She would laugh. At most she would say is yes or no. How you ask the question, is how she responds," she said of her mother, who was once a self-assertive woman who ran her own business.

Audrey's experience accounts for seven per cent of the T&T population that may be diagnosed with dementia. Alzheimer's is just one type of disease associated with dementia, a non-specific syndrome which affects cognitive areas such as memory, attention, language and problem-solving.

According to the Medical News Today Web site, other diseases associated with dementia are vascular dementia (caused by problems in supply of blood to the brain ie a stroke), frontotemporal dementia (progressive deterioration of the frontal lobe of the brain), semantic dementia (language) and dementia with Lewy bodies (spherical structures in the brain that damage brain tissue). Audrey's testimony as caregiver for her mother was part of the discussion on dementia: Awareness of Disease and Impact as part of the University of the West Indies' Research Expo last week.

The Faculty of Medical Sciences hosted the swift hour-long presentation at UWI's Engineering Building.

"Seventy per cent of dementia is Alzheimer's," said Dr Gershwin Davis, a senior lecturer in chemical pathology of UWI's Medical Science faculty, as he explained the disease.

Globally, Alzheimer's affects 16 per cent women and 11 per cent of men who are over the age of 65.

Statistics also reveal that this degenerative disease affects one in ten people in that age group.

He said the challenge is measuring dementia since it moves from no impairment to very mild, to mild cognitive to moderate stages of debilitation. Diagnostic criteria involve memory, language, motor activities, failure to recognise and executive functioning.

Thus the question raised by Human Anatomy Prof Amanda McRae in her presentation, "Are we prepared for the impact of the Dementia Tsunami in T&T?"

In a prevalence dementia study conducted at geriatric homes and senior activity centres in north Trinidad and the social welfare office in Tunapuna, Prof McRae said age was the strongest predictor among the 2,000 who were randomly selected for the survey.

Prof McRae also suggested that risk prevention is possible. She listed aerobic exercise, an active social life, intellectual activities and a healthy diet as ways to delay or prevent an element of the disease.

That human interaction as someone gets older should be maintained, said Dr Nelleen Baboolal, a senior lecture in psychiatry. It helps delay the course of dementia. She also noted that 15 per cent of dementia is reversible, once there is early diagnosis.

However, she noted that 50 per cent of patients who suffer from mental destabilisation are not properly diagnosed.

Although there is no cure for Alzheimer's or dementia, Dr Baboolal said there are several treatments that can prolong memory, providing three to five extra years of working memory.

Some of the risk factors for dementia are age, family history, genetics, high cholesterol, high blood pressure or head trauma.

## Targeting Alzheimers

**UWI research could lead to a greater understanding of the disease and early detection of a disorder that affects millions worldwide**

By: Mark Fraser

Sept. 15, 2013



**ANALYSING:** UWI researchers, from left, Prof Amanda McRae, Dr Nelleen Baboolal and Dr Gershwin Davis, with fellow researcher in the laboratory. —Photo courtesy Mark Hardy

Alzheimer's Disease (AD) is the sixth leading cause of death in the USA and the numbers are rising locally and internationally. By 2030 the numbers of persons affected by the disease in the developed world is expected to double and then triple by 2050. For over a decade researchers at The University of the West Indies have been focusing on gaining a greater understanding of the disease and finding ways for early detection. The researchers have made significant strides in Alzheimer's and dementia research in Trinidad and Tobago.

Although there is no cure for Alzheimer's, a brain disease that affects millions and places tremendous demands on caregivers and family members, treatment is available and research, like the work being done at UWI, provides hope.

In 2003, Dr Nelleen Baboolal, a senior lecturer in Psychiatry Dr Gershwin Davis, a Senior Lecturer in Chemical Pathology and Prof Amanda McRae, Prof of Human Anatomy at the Faculty of Medical Sciences at the St Augustine Campus, began developing a three tiered project that could yield breakthrough results by examining not only the epidemiology of Dementia, but the associated risk factors; and biomarkers for the disease.

The project is certainly revolutionary, as it has the potential for developing a serum screening biomarker for the disease that could introduce a paradigm shift in the way we approach the health care maintenance of the elderly. This is due to the fact that this marker would provide a universal means to differentiate Alzheimer's Disease (AD) from other dementias, as well as establish early detection of the disorder.

But what is a biomarker A biomarker is a substance such as an antibody or protein which is usually present in either the cerebrospinal fluid or blood. The team explained in detail that according to the criteria of the Consensus Report of the Working Group on Molecular and Biochemical Markers of AD, an ideal biomarker should be: reliable; non-invasive; simple to perform; inexpensive; able to detect a fundamental feature of AD neuropathology; and validated in neuropathologically confirmed AD cases (to be precise —be able to detect AD early in its course and distinguish it from other dementias).

For these UWI researchers, the most exciting milestone occurred in 2008, after conducting a workshop entitled "Biomarkers for Dementia—Is there a role" at the American Association of Clinical Chemistry Conference in Washington DC.

"This attracted the attention of a major UK-based diagnostic company. Subsequently collaboration developed between this company and UWI to further the development of a diagnostic biomarker for Alzheimer's disease," Dr Davis explained.

But this was not the only success for the team, the research also helped in initiating investigations about caregiver burden, the extent of dementia in nursing homes versus senior centres and in completing preliminary research on cognitive impairment in diabetics in Trinidad and Tobago.

"This is a collaborative effort not on a specific project but on the theme Alzheimer Disease and Dementia and Mild Cognitive Impairment (MCI). To that end we established and incorporated Dementia Awareness and Research of Trinidad and Tobago (DARTT), a nonprofit company in order to better pursue our research goals and to extend the awareness of Dementia to the general population," he added during an interview in STAN magazine in 2010.

"This collaboration has benefited from the expertise of Prof Surujpal Teelucksingh of The University of the West Indies and Prof Robert Stewart of the Institute of Psychiatry, King's College, London. Our collaborative efforts have generated several publications, book chapters, workshops and conference presentations at international conferences including the International Conference on Alzheimer Disease, Vas Cog, American Association of Clinical Chemistry Conference and Caribbean Health Research Conference."

Education about the disease is integral to effective health care and over the years these UWI researchers, through the DARTT foundation, were able to heighten public awareness of Dementia and help to reduce the associated stigma by focusing on the caregivers and contributing to the literature.

In October they will host a workshop on 'Targeting Dementia' at The UWI Research Expo and information on the disease will be showcased at the UWI Research Expo exhibit at the JFK Auditorium from October 3rd-5th.

In 2013, Drs Baboolal and Davis were jointly successful in being awarded a TT\$550,000 grant from the UWI- TT Research, Development and Impact (RDI) Fund to pursue a project entitled "Mitigating the Dementia Tsunami in Trinidad and Tobago". This project seeks to determine the impact of dementia and its prevalence in persons aged 60 and above in Trinidad and Tobago. The study will also determine the associated cost and implications for the family and caregivers, health care system and economy of Trinidad and Tobago.

An important goal of this project is to raise national and international awareness and funding for development of local research evidenced policies, programmes and medical interventions targeted at defeating the disease of dementia in our region through obtaining accurate, factual information on the prevalence of dementia in our society. Other members of this multi-disciplinary research team include Prof McRae, Dr Stewart, Prof Karl Theodore and others from the HEU, and Dr Gladys Maestra (University Zulia, Maracaibo, Venezuela). This project is an example of the research the RDI Fund seeks to encourage on the UWI St Augustine Campus through its targeted funding programme: research projects that address a pressing developmental need, plan for impact throughout implementation, and enable knowledge mobilisation through active engagement with stakeholders.

The project is timely, to say the least, as a dramatic demographic change is occurring worldwide wherein the oldest segments of the population are increasing at the fastest rate.

By 2015 in Trinidad and Tobago, the age group under 15 years old will fall to 23.9 per cent, with the group over age 65 increasing to 7.5 per cent of the total population. Trinidad and Tobago's population is following the world wide aging trend. What is looming for Trinidad and Tobago as its population ages How will we cope with the dementia epidemic Are we prepared and what measures will be adopted to meet the socioeconomic demands of dementia These are some of the questions being addressed by the study.

Although the greatest risk factor is increasing age and most people with the disease are 65 years and older according to the Alzheimer's Association, it isn't just an elderly disease. In fact, up to five percent of people with the disease have early onset, which means that symptoms may appear in the forties and fifties and get progressively worse.

While in the early stages memory loss is mild, in the later stages the individual may lose the ability to communicate with others and the activities of daily living become all but impossible. In fact according to CNN medical correspondent, Dr Sanjay Gupta, safety becomes a major challenge as six out of ten of persons with AD will wander and become lost.



"As things stand now, people with dementia are largely ignored," Gupta added.

In the news recently, two Dutch nurses who wanted to provide the best healthcare for their parents established a Dementia Village, in Hogewey; complete with barbers, chefs and grocers specifically trained to service this small community.

Worldwide the focus is on treatment, finding better ways to prevent the disease from developing and delaying its onset. Education is key not only to those affected but on a national scale particularly during Alzheimer's month in September.

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