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DEMENTIA CARE RESEARCH (RESEARCH PROJECTS; NONPHARMACOLOGICAL)

A community-based study of reporting demographic and clinical information concordance between informant and cognitively impaired participants

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Abstract

Background: We studied concordance between informants' and cognitively impaired participants' reporting of demographic and clinical information in a community-based cohort study.

Method: As part of the community-based Brain Attack Surveillance in Corpus Christi-Cognitive (BASIC-C) project, households in Nueces County, Texas, USA, were randomly identified. Participants ≥ age 65 were recruited using door-to-door (5/1/2018-3/15/2020) and phone (04/20/2020-current) recruitment. Individuals with possible cognitive impairment were identified using the Montreal Cognitive Assessment (MoCA) during door-to-door recruitment and Telephone Montreal Cognitive Assessment (T-MoCA) during phone recruitment. Participants who scored ≤25 and ≤18 on the MoCA and T-MoCA respectively were eligible for participation. Named informants and participants both answered questions regarding the participant's demographics and health status. Models were generated to examine the predictors that influence concordance between informant and participant answers. Predictors in the model included participants' age, gender, ethnicity, degree of cognitive function (estimated by MoCA/T-MoCA score), and relationship to informant.

Result: Table 1 provides the concordance between participant and informant answers. Overall concordance was high. Female participants were two and a half times more likely to have concordant answers about date of birth with informants than non-spouses and male participants, and spouses were three and a half times more likely to agree with participants on date of birth than non-spouses. (Table 2). Degree of cognitive function of the study participant also showed a large effect on concordance based on the question of whether the participant was diagnosed with dementia ($p < .001$) (Table 4). Other relationships in comparison to child, including other family member and friend/neighbor/other, were associated with concordance of answers to participant educational attainment and high blood pressure diagnosis (Table 3 and 5). Questions about participant diagnosis of diabetes, heart disease, stroke, and alcohol

consumption, had no significant predictors. Ethnicity was not a significant predictor for any question.

Conclusion: Though most of our concordance rates were >80%, in studies that ask demographic and health history questions of cognitively impaired participants, the gold standard for "true" information remains uncertain. Our results, along with future research, may indicate that in these scenarios, studies should consider supplementing participant responses with informant contributions.

Table 1: % Concordance between Participant and Informant Answers

DOB	80.30
HBP Dx	81.21
Diabetes Dx	88.79
Heart disease Dx	79.39
Stroke Dx	88.18
Dementia Dx	87.57
Alcohol use	59.39
Amt of Education	84.24
Excluded from Modeling: less than 10% discordance	
Sex	99.39
Race	91.76
Ethnicity	97.27
Smoking Status	97.57

**DOB refers to date of birth of participant*
**HBP Dx refers to diagnosis of high blood pressure of participant*
**Drinking Status refers to number of alcoholic drinks consumed by participant weekly*
**Dx refers to diagnosis*
**Amt of Education refers to highest grade level completed*
**Smoking Status refers to whether participant is a smoker or non-smoker*

Table 2: Predictors of concordance of answering "Date of Birth" question

	Odds Ratios	
Participant characteristic	Point Estimate	95% Confidence Intervals
Age	1.166 (a)	(0.842,1.613)
Sex (Female vs Male)	2.479 **	(1.313, 4.681)
Ethnicity (MA vs NHW)[1]	0.989	(0.501, 1.954)
Cognitive Function[2]	0.823 (a)	(0.577,1.174)
Relationship		
Other family member vs child	0.566	(0.272, 1.176)
Friend/neighbor/other vs child	0.382	(0.129, 1.129)
Spouse/partner vs child	3.402**	(1.350, 8.575)

** *p = .001 -.01*
[1]*MA refers to Mexican American, NHW refers to Non-Hispanic White*
[2]*Cognitive function refers to MoCA and T-MoCA scores; higher scores suggest lower cognitive function*
(a) OR for a 1 standard deviation change in the continuous predictor.

Table 3: Predictors of concordance of answering "Education" question

	Odds Ratios	
	Point Estimate	95% Confidence Intervals
Age	1.505* (a)	(1.038, 2.181)
Sex (Female vs Male)	1.175	(0.597, 2.313)
Ethnicity (MA vs NHW)[1]	1.250	(0.604, 2.589)
Cognitive Impairment[2]	0.804 (a)	(0.552,1.172)
Relationship		
Other family member vs child	0.424*	(0.189, 0.948)
Friend/neighbor/other vs child	0.269*	(0.0807, 0.833)
Spouse/partner vs child	2.470	(0.946, 6.448)

**p < .01 -.05*
[1]*MA refers to Mexican American, NHW refers to Non-Hispanic White*
[2]*Cognitive function refers to MoCA and T-MoCA scores; higher scores suggest lower cognitive function*
(a) *OR for a 1 standard deviation change in the continuous predictor*

Table 4: Predictors of concordance of answering "Dementia diagnosis" question

	Odds Ratios	
	Point Estimate	95% Confidence Intervals
Age	1.324 (a)	(0.945,1.855)
Sex (Female vs Male)	1.051	(0.437, 2.523)
Ethnicity (MA vs NHW)[1]	1.743	(0.812, 3.741)
Cognitive Impairment[2]	2.595 *** (a)	(1.839, 3.661)
Relationship		
Other family member vs child	1.260	(0.417, 3.804)
Friend/neighbor/other vs child	0.348	(0.097, 1.250)
Spouse/partner vs child	1.207	(0.392, 3.717)

****p < .001*

[1]*MA refers to Mexican American, NHW refers to Non-Hispanic White*

[2]*Cognitive function refers to MoCA and T-MoCA scores; higher scores suggest lower cognitive function*

(a) *OR for a 1 standard deviation change in the continuous predictor*

Table 5: Predictors of concordance of answering "High Blood Pressure diagnosis" question

	Odds Ratios	
	Point Estimate	95% Confidence Intervals
Age	0.782 (a)	(0.593, 1.032)
Sex (Female vs Male)	1.453	(0.741, 2.874)
Ethnicity (MA vs NHW)[1]	1.767	(0.939, 3.327)
Cognitive Impairment[2]	1.187 (a)	(0.858, 1.642)
Relationship		
Other family member vs child	0.868	(0.373, 2.020)
Friend/neighbor/other vs child	0.385 *	(0.149, 0.998)
Spouse/partner vs child	1.539	(0.627, 3.774)

**p < .01 -.05*

[1]*MA refers to Mexican American, NHW refers to Non-Hispanic White*

[2]*Cognitive function refers to MoCA and T-MoCA scores; higher scores suggest lower cognitive function*

(a) *OR for a 1 standard deviation change in the continuous predictor*