Memory Disorder Patient-Caregiver Discrepancies of Patient Mood Ratings and their Associations with Patient Functional Status and Increased Caregiver Burden

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Background

- Patient-caregiver discrepancies are common in QOL and symptom reports
- Caregiver ratings are often more severe than patients', and decrease over time.
- Patient mood can be difficult to correlate with disease progression due to symptom unawareness.
- Study Goal: Examine clinical correlates of mood discrepancies in neurocognitive disorders.

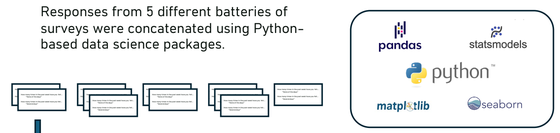
Patient Population

- **Data Collection**: Surveys sent to caregivers and/or completed with patients in-clinic.
- **Period**: 2017-2022, Memory Disorders Clinic, Univ. of Colorado.
- **Data Points**: 3319 visits, 1361 patients.

Demographics	N (%)
Age (mean)	63.5 (SD=14.0)
Gender:	
Male	726 (51.2%)
Female	691 (48.7%)
Race:	
White	1111 (77.5%)
Other/NA	126 (8.7%)
Black/African American	103 (7.1%)
Asian	40 (2.7%)
Unknown	37 (2.6%)
American Indian and Alaskan Native	7 (0.4%)
Multiracial	5 (0.3%)
Native Hawaiian or other Pacific Islander	5 (0.3%)
Medicaid:	
No	948
Yes	283
Unknown	288
Medicare:	
No	857
Yes	707
Unknown	6

Preprocessing Pipeline

Responses from 5 different batteries of surveys were concatenated using Python-based data science packages.



n=1181

n=2240

Physician and clinic notes exported from EpicCare®, were scraped for survey responses and dates using custom functions.

n=3319

Quality control: duplicate and erroneous data were removed through a combination of automated and manual techniques. Incomplete data were estimated or removed in accordance with National Alzheimer's Coordinating Center guidelines.

date	mrn	PHQ-9	GAD-7	MOCA	...
10/17/19	111	7	10	26	
12/4/20	222	NaN	12	NaN	
2/13/18	333	5	NaN	30	
...	333	6	11	25	

*NaN = Not a Number = missing data

Survey responses from different sources were collapsed into single columns, preserving date and demographic information. Text/string data was converted to numerical data using mappings specific to each survey.

$NPIQ_{anx}$		GAD		Anxiety discrepancy
3		2		1
1	−	3	=	-2
NaN		NaN		NaN
2		2		0

Patient-Caregiver depression and anxiety discrepancies were calculated by converting Patient Health Questionnaire-9 (PHQ-9) and Generalized Anxiety Disorder-7 (GAD-7) filled out by patients to Z-scores, and subtracting them from Z-scored Neuropsychiatric Inventory Questionnaire (NPI-Q) subscales for depression and anxiety that were completed by caregivers on the same date.

Preprocessing scripts and functions will be made available at github.com/gordonmatthewson

Results

Table 1: Measures of interest by demographic

Value (SD, n=)	Male	Female
Age	65.09 (13.89, n=1539)	65.83 (14.27, n=1577)
Mean Score:		
MOCA	19.78 (6.22, n=597)	19.77 (6.06, n=627)
FAQ	13.51 (9.40, n=540)	13.04 (9.44, n=560)
PHQ-9	7.00 (6.47, n=552)	6.65 (6.05, n=547)
GAD-7	4.89 (5.39, n=481)	5.19 (5.63, n=494)
NPI-Q Severity	8.20 (6.92, n=461)	7.91 (6.43, n=478)
NPI-Q Distress	9.97 (9.15, n=521)	9.79 (9.02, n=537)
ZBI	6.08 (3.77, n=402)	5.78 (3.78, n=418)
Anxiety Discrepancy (3 point scale)	.26 (.97, n=250)	.25 (.94, n=257)
Depression Discrepancy (3 point scale)	.10 (.98, n=299)	.17 (1.00, n=299)

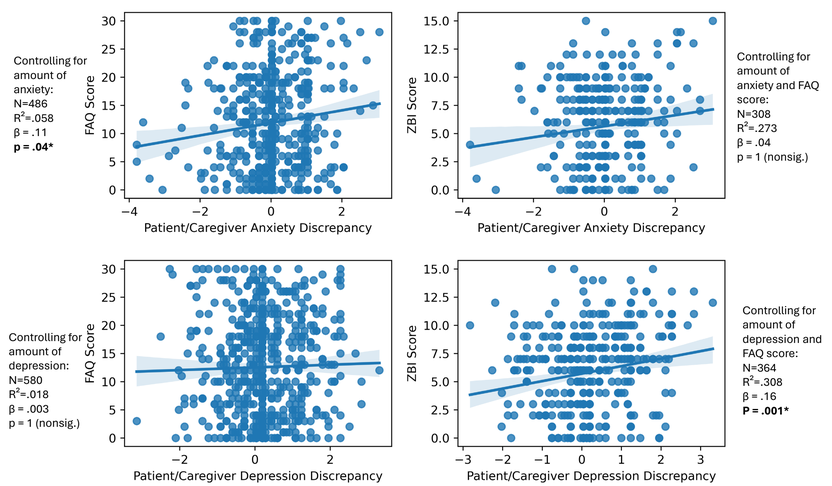
MOCA = Montreal Cognitive Assessment, FAQ = Functional Activities Questionnaire, PHQ-9 = Patient Health Questionnaire 9, GAD-8=Generalized Anxiety Disorder 7 Questionnaire, NPI-Q = Neuropsychiatric Inventory Questionnaire Severity Score, ZBI = Zarit Burden Interview

Table 2: Measures of interest by diagnosis

Value (SD, n=)	AD	MCI	PCS	SCI	Other
Male	333 (48.7%)	251 (47.3%)	141 (58.2%)	107 (48.6%)	729 (48.9%)
Female	350 (51.2%	279 (52.6%)	101 (41.7%)	113 (51.3%)	762 (51.1%)
Age	77.44 (6.54, n=676)	70.27 (9.06, n=543)	47.89 (13.31, n=246)	59.31 (14.33, n=237)	62.34 (13.25, n=1564)
MOCA	15.31 (5.22, n=277)	21.69 (3.55, n=251)	24.45 (4.2, n=98)	26.87 (2.66, n=105)	19.07 (6.12, n=561)
FAQ	17.58 (8.42, n=291)	6.15 (5.77, n=202)	6.58 (6.57, n=40)	3.79 (5.93, n=53)	14.82 (9.26, n=564)
PHQ-9	4.69 (4.77, n=207)	5.18 (5.43, n=219)	10.65 (7.4, n=96)	7.1 (6.08, n=108)	7.76 (6.48, n=513)
GAD-7	3.79 (4.66, n=168)	3.82 (4.54, n=203)	7.31 (6.01, n=88)	4.26 (4.34, n=112)	5.83 (6.06, n=453)
NPI-Q Severity	8.69 (6.99, n=266)	4.98 (4.65, n=153)	10.84 (7.22, n=37)	5.27 (3.95, n=22)	8.56 (6.79, n=497)
NPI-Q Distress	11.13 (9.65, n=280)	5.58 (6.71, n=185))	12.67 (10.3, n=39)	6.43 (5.65, n=46)	10.61 (9.14, n=551)
ZBI	6.66 (3.32, n=226)	4.12 (3.28, n=149)	7.0 (3.49, n=20)	3.91 (3.83, n=35)	6.35 (3.91, n=422)
Anxiety Discrepancy (3 point scale)	0.32 (0.94, n=134)	0.29 (0.93, n=106)	0.14 (0.97, n=28)	0.0 (1.2, n=15)	0.2 (0.99, n=243)
Depression Discrepancy (3 point scale)	0.32 (0.88, n=159)	0.04 (0.91, n=122	0.22 (1.34, n=32)	0.18 (0.95, n=17)	0.03 (1.05, n=297)

AD = Alzheimer's Disease, MCI = Mild Cognitive Impairment, PCS = Post Concussion Syndrome, SCI = Subjective Cognitive Impairment

Patient/Caregiver discrepancies in ratings of patient mood, and their relationship to Zarit Burden Interview (ZBI) and Functional Activity Questionnaire (FAQ) responses



Conclusions

- Larger discrepancies between patient and caregiver of ratings of patient anxiety are weakly but reliably related to loss of functional status
- Larger discrepancies between patient and caregiver ratings of patient depression are related to higher caregiver burden
- Discrepancies in anxiety were unrelated to caregiver burden, while discrepancies in depression were unrelated to functional status

Future Directions

- Gender Differences: Assess gender impact on discrepancy.
- Longitudinal Analysis: Observe changes over time.
- Mediation Analyses: Determine mediators.
- Diagnostic Interaction: Compare across conditions.

References

1. Andrieu, S., Coley, N., Rolland, Y., Cantet, C., Arnaud, C., Guyonnet, S., ... & Provost, L. (2016). Assessing Alzheimer's disease patients' quality of life: discrepancies between patient and caregiver perspectives. *Alzheimer's & Dementia*, *12*(4), 427-437.
2. Cines, S., Farrell, M., Steffener, J., Sullo, L., Huey, E., Karlawish, J., & Cosentino, S. (2015). Examining the pathways between self-awareness and well-being in mild to moderate Alzheimer disease. *The American Journal of Geriatric Psychiatry*, *23*(12), 1297-1306.
3. Alexander, C. M., Martyr, A., Gamble, L. D., Savage, S. A., Quinn, C., Morris, R. G., ... & IDEAL programme research team. (2021). Does awareness of condition help people with mild-to-moderate dementia to live well? Findings from the IDEAL programme. *BMC geriatrics*, *21*, 1-15.
4. Ydstebø, A. E., Bergh, S., Selbæk, G., Benth, J. Š., Brønnick, K., & Vossius, C. (2018). Longitudinal changes in quality of life among elderly people with and without dementia. *International Psychogeriatrics*, *30*(11), 1607-1618.

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