

# Characteristics of Electronic and Paper Questionnaire Users in an Academic Memory Clinic

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## Background

- Patient reported outcomes (PROs) are increasingly essential for gathering information needed for clinical decision-making.
- Due to the time limitations of modern clinical care, and especially due to the increasing prominence of telehealth as illustrated by the recent COVID-19 pandemic, there is an increasing need for PROs to be collected remotely, often before the clinical appointment takes place.
- However, electronic methods of data-collection can present unique challenges that risk excluding certain groups.
- Establishing which, if any, demographics of patients are more likely to be missed when a physician orders an electronic survey will allow researchers to subsequently find interventions to ensure that these patients are accounted for.
- We investigated demographic, disease-related, and caregiver-related characteristics of those who filled electronic surveys, paper surveys, or no surveys at all.

## Methods

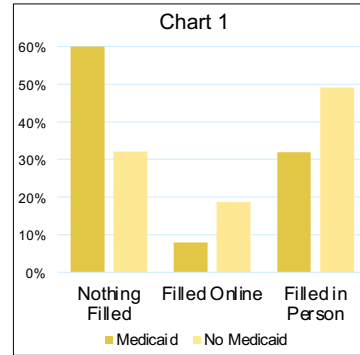
- This was a retrospective, descriptive study of patients and caregivers in an academic memory clinic (N = 785), with a total of 1136 office visits (average 1.4 visits per patient).
- Patients and caregivers were sent an electronic questionnaire to fill out ahead of their visit and provided paper in the office if they did not fill out the electronic version.
- The data were analyzed using mixed-effects logistic regression models.

|                         | Nothing Filled | Filled Online | Filled in Person |
|-------------------------|----------------|---------------|------------------|
| Age                     | 55.0 +/- 16.9  | 67.9 +/- 15.7 | 63.8 +/- 17.7    |
| Gender (% Female)       | 291 (45.4%)    | 133 (47.4%)   | 366 (46.2%)      |
| Race (% Caucasian)      | 291 (76.6%)    | 133 (77.4%)   | 366 (74.3%)      |
| Ethnicity (% Hispanic)  | 291 (11.3%)    | 133 (4.8%)    | 366 (7.4%)       |
| Medicaid (% of Total)   | 90 (31.8%)     | 12 (9.7%)     | 48 (14.0%)       |
| <b>Patient Survey</b>   |                |               |                  |
| NPIQ Severity Total     | 6.2 +/- 5.9    | 10.0 +/- 6.4  | 5.9 +/- 5.3      |
| FAQ Total               | 9.7 +/- 8.1    | 15.2 +/- 8.1  | 11.9 +/- 9.3     |
| MoCA Total              | 23.1 +/- 4.8   | 18.1 +/- 6.2  | 19.0 +/- 6.8     |
| FAB Total               | 15.7 +/- 2.2   | 13.8 +/- 3.7  | 14.2 +/- 4.8     |
| <b>Caregiver Survey</b> |                |               |                  |
| Zarit Total             | 6.5 +/- 0.7    | 0.9 +/- 2.6   | 6.3 +/- 3.8      |
| NPIQ Distress Total     | 4.6 +/- 4.8    | 13.2 +/- 10.4 | 6.8 +/- 6.8      |

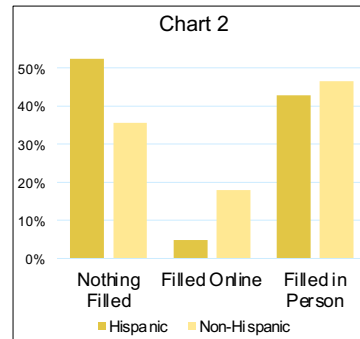
NPIQ = Neuropsychiatric Inventory Questionnaire; FAQ = Functional Activities Questionnaire; MoCA = Montreal Cognitive Assessment; FAB = Frontal Assessment Battery; Zarit = Zarit Caregiver Questionnaire

|   | Nothing Filled | Filled Online | Filled in Person |
|---|----------------|---------------|------------------|
| Alzheimer's Disease                                       | 27 (16.7%)     | 47 (29.0%)    | 88 (54.3%)       |
| Lewy Body Dementia  | 3 (20.0%)      | 3 (20.0%)     | 9 (60.0%)        |
| Mild Cognitive Impairment                                 | 86 (40.6%)     | 29 (13.6%)    | 99 (46.3%)       |
| Post Concussion Syndrome                                  | 48 (66.7%)     | 4 (5.6%)      | 20 (27.8%)       |
| Primary Progressive Aphasia                               | 2 (5.9%)       | 5 (14.7%)     | 27 (79.4%)       |
| Subjective Cognitive Impairment                           | 36 (57.1%)     | 4 (6.4%)      | 23 (36.5%)       |
| Behavioral Variant Frontotemporal Dementia                | 1 (4.4%)       | 8 (34.8%)     | 14 (60.9%)       |
| Major Neurocognitive Impairment (not otherwise specified) | 20 (30.1%)     | 18 (27.7%)    | 27 (41.5%)       |
| Developmental Disability                                  | 10 (58.8%)     | 2 (11.8%)     | 5 (29.4%)        |
| Other   | 37 (43.0%)     | 9 (10.5%)     | 40 (46.5%)       |
| Primary Psychiatric Disorder                              | 16 (64.0%)     | 2 (8.0%)      | 7 (28.0%)        |
| Vascular Disease  | 5 (35.7%)      | 2 (14.3%)     | 7 (50.0%)        |
| Total   | 291 (36.8%)    | 133 (16.8%)   | 366 (46.3%)      |

## Results



\*Those on Medicaid (our measure for socioeconomic status) were less likely to have caregiver forms filled beforehand or in the clinic.



\*Hispanic ethnicity correlated with decreased use of electronic questionnaires ( $\beta = -1.3$ ,  $p < 0.015$ ,  $CI[-2.4; 0.26]$ ).

- There was an effect of patient age on whether a caregiver filled a survey by computer ( $\beta = 0.04$ ,  $p < 0.001$ ,  $CI[0.02; 0.05]$ ), on paper ( $\beta = -0.03$ ,  $p < 0.001$ ,  $CI[0.01; 0.04]$ ), or not at all ( $\beta = -0.05$ ,  $p < 0.001$ ,  $CI[-0.06; -0.04]$ ).
- Neurobehavioral symptoms correlated with increased use of electronic questionnaires by caregivers ( $\beta = 0.2$ ,  $p < 0.001$ ,  $CI[0.1; 0.2]$ ), as did increasing patient functional disability ( $\beta = 0.1$ ,  $p < 0.001$ ,  $CI[0.0; 0.1]$ ).
- The severity on NPIQ was associated with increased likelihood of filling caregiver surveys on computer ( $\beta = 0.18$ ,  $p < 0.001$ ,  $CI[0.11; 0.25]$ ).
- Patient gender and race showed no effect.

## Conclusions

- The effects due to patient age seem to indicate greater caregiver involvement as patients get older. This seems to be a similar effect as is seen with the increased FAQ score.
- The increased likelihood of filling out online surveys seen with increased NPIQ scores might indicate that caregivers find it easier to provide difficult information electronically rather than in person.
- Additional considerations should be given to expand accessibility of PRO surveys to those of lower socioeconomic status and ethnic minorities.

## References

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