

Assessing the Individualized Needs and Goals of Caregivers in the EHR: Development of the COPE-ING Measure

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OBJECTIVE:

1. Obtain care partner and dementia professional feedback on initial Caregiver Outcomes of Psychotherapy Evaluation-Individualized Needs and Goals (COPE-ING) item pool.
2. Explore preliminary test-retest reliability and construct validity of the COPE-Individualized Needs and Goals.



DESIGN, SETTING, AND PARTICIPANTS:

- 52 participants (N=28 caregivers; N=24 dementia professionals) were recruited to provide feedback on the preliminary COPE-ING measure
- Participants rated each item on a Likert scale (1- Not important at all to 5- Extremely Important)
- Qualitative feedback on the wording of each item was also obtained
- Survey was conducted online via Redcap May-September 2023



INTERVENTION AND IMPLEMENTATION:

- Dementia caregivers and professionals were identified through word of mouth and recruitment flyers at community outreach events and neurology clinics
- 37% of professionals surveyed were non-white
- Caregivers from over seven neurodegenerative conditions were surveyed



RELEVANCE: These findings outline the initial development of the COPE-ING, a novel measure designed to be embedded into the EHR to capture the individualized needs and goals of dementia caregivers. The COPE-ING tool holds promise for use in ePCTs, by identifying caregiver needs and goals and helping to evaluate effectiveness of interventions tailored to specific caregiving needs.



MEASURES: Table 1: Example items from the COPE-ING

I want to understand more about dementia, memory or thinking problems and what to expect as things change in the future	I want information on how to find and pay for caregivers in the home
I want help finding meaningful activities at home or community programs for the person I care for, such as senior centers, adult day care, respite and support groups	I want help understanding the cost and types of housing options for right now or in the future, such as independent living, assisted living and memory care
I want help finding caregiver programs, such as education, trainings, classes or support groups	I want help with legal, medical, or financial questions such as medical power of attorney, long-term care insurance, disability paperwork or medical insurance
I want to learn about brain health for myself and the person I care for, such as exercise, nutrition, or tips for getting good sleep	I want to learn about transportation options for me or the person I care for
I want to learn better ways to reduce my own stress, depression, frustration or anxiety	I want to learn about research studies or clinical trials for me or the person I care for



RESULTS:

- All 15 items were endorsed as important by caregivers and professionals.
- Qualitative feedback included changing wording to a lower literacy level, switching the word 'cognitive impairment' to 'dementia' and including specific examples of services
- Efforts made to solicit feedback from individuals with diverse backgrounds were successful