Digital Dementia Female Caregivers: Challenges, Feedback, and Opportunities

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Background

More than 15 million individuals care for someone with Alzheimer's Disease Related Dementia (ADRD) in the US. Women not only are more likely to develop dementia compared to men, but women also comprise more than 60% of these caregivers (CG). One third are in the "sandwich generation" who care for an older adult and minor children.

Caregiving however, has come with a health cost. Many female CG have multiple medical co-morbidities, including hypertension and increased risk of heart disease, when compared to female non-CG.

In addition, women who provide care for 9+ hours/day have an increased risk of depression and coronary heart disease. This risk rises to 65% when considering ADRD CG. These issues affect women specifically, as there are 2.5 women for every man who lives with and cares for an individual in need.

Methods

- Qualitative interviews were performed on 50 female ADRD CG. Open-ended questioning on :
  - main challenges of caregiving
  - general experience of the healthcare system
  - means of gathering information online and
  - short feedback from a demo experience of a web-based CG screener tool (Neurocern) was collected and main themes were identified.
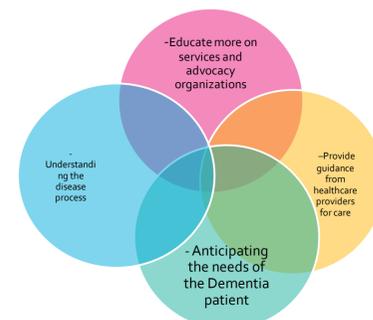
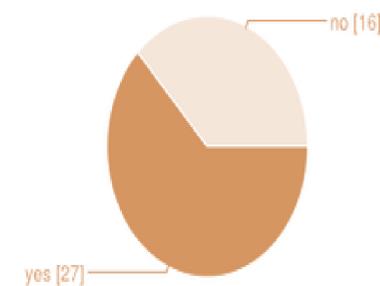## Figures
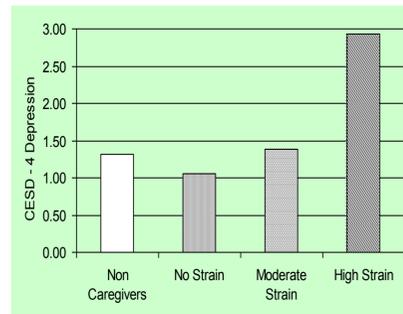
Roth et al., 2009

Neurocern – Web based Guidance for Caregivers
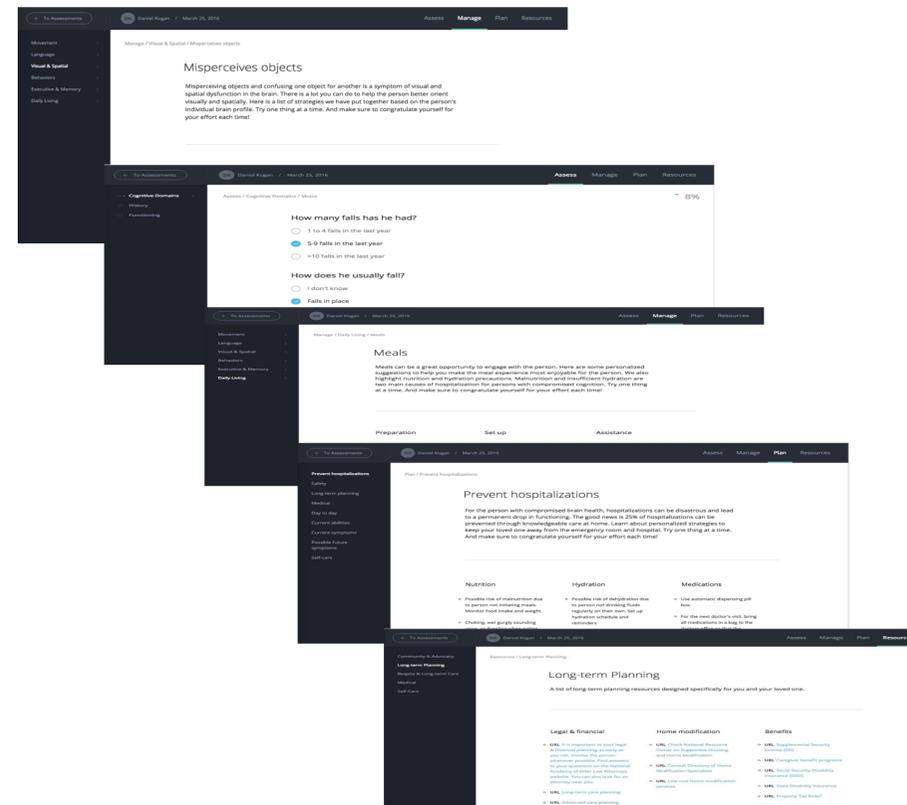
Challenges and Needs faced by Dementia Caregivers

Family history of dementia- AD, senility

no [16]

yes [27]

Results

Main challenges of caregiving included understanding, anticipating and meeting needs of the patient's symptoms. Most CG wanted care recommendations that were relevant to the patient's stage and type of ADRD. Lack of guidance and communication from healthcare provider networks was reported by most CG. More than 60% of CG were unaware of dementia or disease-specific advocacy organizations .

After the web-based CG screener tool demo, CG reported feeling "more informed to communicate ADRD symptoms to the patient's doctor" and receptive to "receiving personalized ADRD care recommendations online".

Pilot Application of Neurocern at the Rush Heart Center For Women
Targeting female CG with relevant disease and care information using web-based technology may be a worthwhile digital population health initiative. Offering this technology to female ADRD CG with heart disease may lead to improved CG heart health.

The RHCW's Cardio Cognitive Clinic is multi-specialty clinic that collaborates with experts from preventive and onco-cardiology, dietary and nutrition services and cognitive neurology to provide patient centered care in an outpatient setting. In a preliminary survey, the RHCW has identified that family history of dementia is common in women with heart disease (therefore conferring them at risk for dementia) and also raises concerns of caregiving for loved one's with dementia.

We are presently recruiting 50 women from the Clinic who caregive to participate in a 6 month Caregiver Intervention study using the web based programming in Neurocern, to monitor levels and change in caregiver stress, biological inflammatory markers of stress and overall quality of life.

Conclusions

By employing a web based Caregiving tool – Neurocern - to women with heart disease who caregive at the RHCW, we will be able to explore strategies of positive self care and care of loved ones with dementia in a non traditional setting. This pilot adds to the comprehensive services at the RHCW, that aim to optimize cardiovascular risk management and preserve optimal brain health in women who have cardiovascular risk factors or heart disease.