DEMENTIA AND CAREGIVERS

Modeling the Impacts of Stress of Family Caregivers on the Quality of Care and Disease Progression to Inform Policy & Practice Interventions

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Introduction: This project is on Dementia and Caregivers. Specifically, it highlights the stress that family members who play an additional role as caregivers to older family members like parents who suffer dementia, and how these stressors impact on the quality of life of the caregivers, and the quality of care that are offered by same caregivers and its consequential impact on progress of the dementia and other associated demand on the healthcare system at large.

Part 1 of the project will thus capture the scope of the model (i.e. questions that this model would seek to address and the initial boundaries of the model by mentioning the key endogenous, exogenous and ignoring factors.)

Project Questions: Throughout the project, we shall attempt to use all three traditions of Dynamic modeling (one at a time or a hybrid, as may be relevant to the stage of exploration) to explore and answer the following questions:

1. How does the role of a family caregiver in dementia care stimulate stress for the caregiver, and how interconnected are these stressors?
2. How could these stressors in turn impact the quality of care that a family caregiver may offer to an older demented family member, like the mother?
3. In what ways will the quality of care by family caregivers impact the natural history and disease progression of the Dementia?
4. To what extent will the disease progress impact the healthcare system in both immediate and long-term?
5. What kinds of interventions could either nip this cascade in the bud or slow the impacts?

Informed by the nature of the questions above, we anticipate using Causal Loop Diagrams (CLD) in Systems Dynamics Modeling (SDM) to initially attempt answering questions 1 & 2 and then use a hybrid of Agent-Based Modeling (ABM) and Discrete Event Simulation (DES) to explore question 3, 4 & 5. We would assume that this modeling process shall run over a period of 5years and will have unit in weeks. We hope that our findings could inform relevant policies and practices.

Based on the above framework, we have identified some variables as endogenous (those to be generated by the model), exogeneous (those with pre-specified calibration as informed by literature or empirical data) and the variable we may want to ignore at the start of the model, though may be useful during the future stages of the modeling process.

Endogenous Variables

i. Family members with Dementia
ii. Progression of the Dementia
iii. Home (of Dementia Patient or FCG)
iv. Family Caregivers (FCGs)
v. Quality of Care offered by FCGs
vi. Personal Goals & Pursuits of FCG
vii. Stressors of FCG (fatigue, sleep disturbances, emotional strain, financial defficulties, deteriorating health status, social isolation etc)

Exogenous Variables

i. Quality of care provided by Primary Care Providers (PCPs)
ii. Available Healthcare Facilities/
iii. Adults day & Long-term homes
iv. Number of PCPs Available
v. Number of people who are dependents of/on FCG

Ignoring Variables

i. Impact of Dementia on Community
ii. Sandwich Generation
iii. The specific clinical subtypes or genetic causes of dementia
iv. Broad macroeconomic variables (e.g., inflation, national unemployment rates) unless they are directly modeled as financial pressures.