Toward An Artificial Cognitive System To Assist Caregivers In Decision-Making For Persons Living With Dementia

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Abstract

Dementia is a term used to describe a collection of neurodegenerative disorders that impact people across the world. The symptoms of the disease progression include recent memory loss and impairment of cognitive functions that create challenges to individuals living with dementia performing daily tasks, making them dependent on caregivers. Due to social and economic matters, caregivers can be either professional or informal, and in some cases, they are members of the patient's family. Investigations suggest that caring for individuals living with neurodegenerative disease is stressful physically, mentally, and emotionally. This study aims to suggest a model of an artificial cognitive system to assist caregivers in dementia care. The methodology applied was design science research (DSR). We have no knowledge of any work that attempted to implement a similar approach, which corroborates with the belief that this is still a cutting-edge technology and novel interdisciplinary area. Our proof-of-concept tried involving artificial cognitive aspects to assistance. It handled the data of the patient to provide information from reliable sources to non-professional caregiver's decision-making regardless of the disease stage. However, it is in a nascent state of development and requires further research to be applied in real scenarios.

Keywords

Artificial cognitive system, Decision-making, Dementia, Caregivers

1. Introduction

Dementia is a group of neurodegenerative disorders. Its symptoms impact cognitive functions such as memory loss and decline of thinking. In addition, it is not a unique disease but represents a group of single or mixed causes of abnormal brain changes that trigger a progressive cognitive impairment. This is not curable so far ("Alzheimer's Association International", 2021). Among the known cognitive impartments, Alzheimer's disease is the most common disease worldwide with at least 50 million people affected, accounting for more than 60% of all people that are living with dementia ("Alzheimer's Association International", 2021). At the time of this writing, 75% of cases of dementia worldwide are not diagnosed (International; University, 2021). However, it may reach 90% in low- and middle-income countries due to restrictions of resources. People with dementia (PWD) with advancing stages normally depends on special supervision continuously from families and caregivers once they do not remember how to perform daily activities. Usually, the family member provides unpaid support and faces complex decision-making related to the patient's care. These people need to have access to practitioners, professionals, or organizations as decision aids. When the PWD still has awareness and thinking capacity, a shared decision-making might be an important tool in an early stage. However, as dementia advances, the caregiver faces multiple inter-related scenarios transforming the decision into a difficult task. The paper is focused on assisting tailored-manner informal caregivers (family member or other person who normally provides the daily care or supervision with no professional expertise) in decision-

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making. The intervention proposed is through a cognitive system (CS). In addition, we aimed to develop resources and began the consolidation of an interdisciplinary knowledge domain to face dementia care and incentive further research.

2. Decision-making and the caregiver of people with dementia

The decision-making ability required from a person acting as the caregiver may expand from finances to end-of-life care and it should be done in a timely manner with often high complexity (Shippee; Rowan; Henning–Smith, 2015). Besides the available care knowledge, the decisions in the dementia care process require a combination of abilities and should vary based on the capacity and will of the patient. This knowledge is needed to make a decision that might vary depending on either the disease stage or health conditions of the patient once neurogenerative diseases such as Alzheimer are highly individualized (Truglio– Londrigan; Slyer, 2019) due to the absence of a standard pathway. Roughly 11 million of people are informal caregivers in USA or almost 3% of US population according to 2020 U.S Census. They are "hidden victims" of dementia once their role can be stressful and exhaustive. We could notice a lack of preparedness to provide care in our study and the number of people with access to professional services is low. For this research purpose, we aimed a shared-decision approach using a theoretical background from certified data sources such as international organizations or healthcare professionals.

3. Methodology

The core of this research is exploring cognitive technologies for the benefit of caregivers to achieve the target we proposed through an experiment to assist the decision-making of caregivers on their basic day-to-day activities. In addition, the methodology is based on design science research methodology (DSRM) due to the novelty of this work. This approach is often used in engineering and information systems areas. We decided to use free databases with data extraction from brain measurements. Then, after an intense search, we found a collection of scans of 150 adults using magnetic resonance imaging (MRI) compiled and freely distributed by OASIS platform. The dataset chosen has cross-sectional and longitudinal information. The OASIS collection consists of both men and women. Here, 72 people were characterized as nondemented throughout the entire study and 64 were considered as demented at the time of their initial visit and remained for subsequent scans, which include 51 individuals with mild to moderate Alzheimer's disease. Fourteen patients were characterized as nondemented at the time of their initial visit and were subsequently characterized as demented at a later visit. Each person was scanned after two or more visits, which was separated by at least one year for a total of 373 imaging sessions (Marcus et al., 2010).

4. Experiment

The experiment was designed on a model to conceptually validate the application of a cognitive system to assist the decision making of caregivers. The experiment is a qualitative and quantitative laboratory study to execute the simulations as a proof-of-concept. Therefore, the cognitive toolkit chosen for experiment purposes is based on the cognitive systems toolkit (CST), which is a project developed by the researchers of the University of Campinas (UNICAMP). Adopting CST, we were able to create a cognitive agent without lock-in to unique architecture and develop simulations for cognitive reasoning, perception, etc. The CST is codelet-based, each codelet is a well-defined agent with main cognitive functions encapsulated in small pieces of code and it can behave fully parallel asynchronously. We considered CST's flexibility, which is a pivotal characteristic, to develop a suitable experiment and to potentially address the needs of caregivers. We built a simple model to run this experiment presented in Section 5, it was written using a few components of CST toolkit (see Fig. 1). We proposed a system with structural knowledge crafted by healthcare professionals and credited support communities. In particular, the domain characteristic can be enhanced by machine learning models, but it will require supervised instructions at the first stage to establish a formalist of knowledge.

5. Experiment

We built the *Attention* codelet that gets information seamlessly from its environment to describe the model proposition. However, for our laboratory study, we inserted a prepared OASIS dataset with the data of the patients from CSV files. For future implementation, it would handle real biometric or physiologic data of the patients either in NRT (near realtime) data or static data, such MRI or similar exams, medical visits, or a real-time health telemetric data of the caregiver. The *Attention* codelet creates memory objects (MO) called *attentionMO* in episodic memory. For our context, an episode is the data from doctor visits or MRI executed. It might be interpreted as sensory memory as well, depending on the need of store or not the information in long-term slots. The next phase is our perceptual codelet named *correlationDetector*, which was responsible for correlation analyses based on statistical theories. Within the codelet, we have implemented the Pearson's correlation coefficient to find out the relationship between variables to statistically know the strength of the relation. The *correlationDetector* should send data to perceptual codelet as memory objects named as *knownPatternsMO*. This MO has data from all previously known patterns received from perception codelets. For this study's purposes, a pattern can be some connection either nonobvious such as normalized whole-brain volume with dementia characterization or something obvious as adult people that got clinical dementia rating from 2 on, he/she has a high likelihood of a need for caregiver supervision.

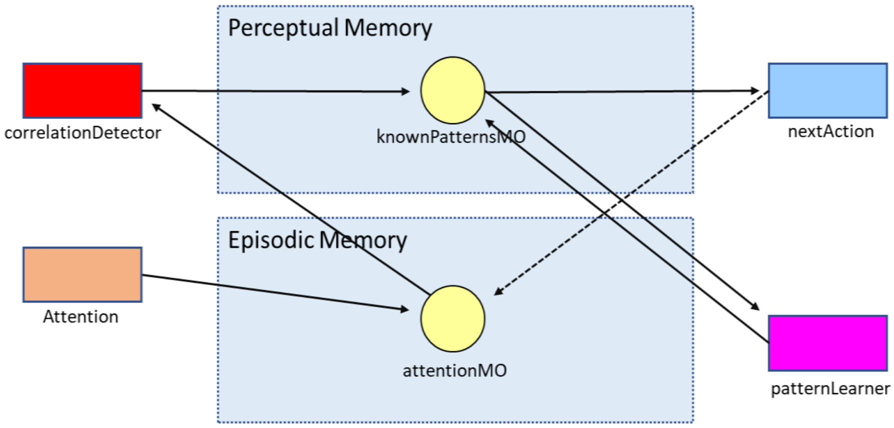

Figure 1: Proposed cognitive model

The *knownPatternsMO* may trigger events simultaneously in two new codelets the *nextAction* responsible for planning activities, has a list of standard information written to support a caregiver as well as provide to the system a kind of "recommendation" to pick up the best what to do next action for each patient stage of dementia progression, as a result, it can assist the end-user in decision-making. The *patternLearner* might receive a signal from perceptual memory regarding the new connection raised from Fig. 1. - Proposed cognitive model *correlationDetector*, this codelet has a role of reasoning and learning from the emerging information. Once *patternLearner* has learned, it can update the *knownPattern* with a new pattern enhancing the perceptual memory. Additionally, we are aware of the potential information path returning a new memory object to the episodic memory to enrich its entries.

We obtained the results of clinical tests such as mini-mental state examination (MMSE) and clinical dementia rating (CDR) from OASIS dataset. Then, we had the current stage of cognitive impairment of the patient from a clinical perspective. The next step was to "teach/train" the system using the categories suggested by the literature for each stage of the impairment: borderline, mild impairment, moderate impairment, moderately severe, severe, and very severe (late stages or end of life). The experiment system will classify the stage of the patient and provide personalized suggestions that potentially assist the decision of the caregiver based on the guidelines of the international Alzheimer and dementia association.

Since learning is iterative, we set the desired accuracy to stop the model. The scale adopted for classificatory algorithm has been considered against the MMSE as Bartfay; Bartfay; Gorey (2013) work where they attempted to create a parallel cognitive scale using MMSE as baseline. The system processes and presents the possible state of dementia pathway according to the MMSE scale. Subsequently, the experiment provides resources to help caregiving through each stage of the disease to enhance knowledge of caregiver.

6. Results and discussion

The system was executed in simulation cycles in which the performance of the system was measured by execution time. From the simulation, we collect the median arithmetic and the standard deviation, 0,032 sec. and 0,033 seconds respectively. The average time (sec) is the total time required for the agent to present result to the user divided by the number of executions, the standard deviation measure expresses the degree of dispersion of a dataset. We decided to use the decision tree algorithm due to the classificatory behavior when compared with other models. The decision tree implemented was J48 built-in by the WEKA project libraries (chosen by convenience). Number of Leaves: 26, Size of the tree: 51, Correctly Classified Instances: 323 or 87.53%, Incorrectly Classified Instances: 46 or 12.46%, Kappa statistic: 0.02 Mean absolute error: 0.05, Root mean squared error: 0.17, Relative absolute error: 93.04 % Root relative square error: 103.91%, Total Number of Instances 369.

7. Conclusion

As technological innovation continuously evolves, our proposed cognitive system, which aims to support dementia care, can contribute to future research on a novel multidisciplinary area. As we could not find similar results, we have identified potential directions for future research to explore these further. The laboratory environment has various limitations compared with the real scenario and its complexities. The cognitive agent should potentially interact with PWDs and their caregivers. In addition, it could “ingest” various environmental variables and extract data of patients from symptoms, such as memory loss and abnormal conditions. Then, this information should be learned and processed to provide assistive information to the decision of the caregiver based on a reliable source. It is not an easy task to build a healthcare system since it must comply with international standards, and it should have low lenience of failures. Our context of dementia care has additional challenges to deal with such as thinking or memory loss or targeting the indirect end-user (the target users are informal cares). We also noticed a lack of instances and varied variables to enhance our machine learning model. The OASIS dataset has a very clear proposal: an open database to support neuroscience research. However, we realized that data from other sources such as laboratory analyses or physiological signals would be good when integrated into the OASIS data to more robust solutions to people with cognitive impairments. Overall, the system has informative behavior. Furthermore, the system is not intended to diagnose or replace a human professional. The proposed system has an innovative characteristic due to the merging of cognitive science and artificial intelligence tailored to assist caregivers of individuals with dementia. It might be an affordable tool to caregivers from low- and middle-income countries due to low resources needed to use it and it was designed to have a simple user interface for individuals that lack digital literacy. For example, it is important to consider that a magnetic resonance might not be available everywhere due to its costs.

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