Project proposal on

ADCare: Smart tools for screening, resource mapping, and increasing awareness of Alzheimer's Disease among population in Bangladesh

Applicant Type: Organization

Name of the Applicant / Name of the Organization: AIMS Lab, United International University

Type of Organization: Private Registration Number: S-10111(United International University) of 2009

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Relationship of the project with organization mandate:

This project will be in significant collaboration with AIMS Lab, which is working to foster research and development in the areas of ICT, smart solutions, intelligent systems, human computer interaction (HCI), brain-computer interface (BCI), rehabilitation engineering and mobile technology for healthcare and disabilities to improving quality of life of people in Bangladesh.

Is there any research/publication on the problem statement? No

HR Plan (Attach CV of the applicant with photo): Please see the attachment.

Project proposal:

The socio-economic structure in Bangladesh barely gives us an opportunity to build awareness of neurodegenerative disorder like Alzheimer's diseases, which is mostly unknown among the population in Bangladesh. Due to the high probability of having Alzheimer's disease among elderly people, such as dementia (which we are going to emphasize on), families suffer both mental and economical stresses. Most of the cases ended up with Alzheimer's dementia (AD) patients not being treated properly and kept beyond the reach of professional resources and facilities. However, there is no effective definite structure in front of us to show how AD affects our society and how we can increase awareness among general people regarding symptoms of AD. This project would help to understand and evaluate the whole situation and healthcare facilities regarding AD, and build a solid structure to help government to increase awareness regarding AD among people through information technology, e.g., ICT. Furthermore, this project would develop a cloud-based system for screening the probability of having AD for an individual and refer to the available facilities when necessary. The project will also build a solid ground to train family members, as well as healthcare personals for basic caregiver training (e.g., Community Health Care Provider/Health Assistant/Medical Assistant) for AD.

Objective

We are going to analyze the situation of AD in Bangladesh based on a large population data focusing on prevalence and facilities. Based on these analyses, we are going to suggest necessary structure to increase awareness among people irrespective of their areas starting with acknowledging AD as a neurodegenerative disorder. The next step would be developing an automated cloud based system that can help individuals in the screening process, as well as referring facilities for AD. One feature of the system would record the response to a set of questionnaires regarding symptoms of AD for a specific individual under a certain user ID. These responses would be sent for classification using a Feed-forward Back-propagation based Artificial Neural Network. The classifier will identify whether the individual has AD or not. The system will also suggest the places where people can go for the available professional resources and existing facilities of AD including caregivers. The system will also include a feature that provides virtual training for caregivers, which could be people in healthcare sectors (both government and non-government organization). Furthermore, one of the family members of a person with AD can have caregiver training to treat that individual.

State of the Art

Alzheimer's disease, which is the most common cause of dementia, is an irreversible neurodegenerative disorder that affects most elderly people demolishing their nerve cells, neurons (mainly, the loss of connections between neurons in the brain) [1]. This slowly leads people towards the loss of cognitive functioning, thinking, remembering, reasoning, and behavioral abilities, and ended up making them unable to perform everyday

necessities. The brain starts a decade, or more before memory and other cognitive problems appear, which is a symptom-free preclinical stage of AD [1]. Memory problems are typically one of the first signs (symptoms vary from person to person) of cognitive impairment related to AD, called mild cognitive impairment (MCI). Eventually, brain tissue shrinks significantly in the severe stage after mild and moderate stages of AD. People with memory and thinking concerns should talk to their doctor to find out whether their symptoms are due to Alzheimer's, or another cause, such as stroke, tumor, Parkinson's disease, sleep disturbances, side effects of medication, an infection, or a non-Alzheimer's dementia. Some of these conditions may be treatable and possibly reversible.

AD is the most common cause of dementia and usually occurs in old age. However, nonfamilial early-onset Alzheimer's disease, which are estimated to account for only 3.5% of total AD, can develop in people who are in their 30s or 40s, showing in their 50s or early 60s [2, 3]. The genetic heritability of AD ranges from 49% to 79%, around 0.1% of which have an onset before age 65 [4–6]. The disease can have devastating effects on the careers, caretakers and family members of patients, including younger people losing their ability to take care of their own needs, or management [7–9].

AD is currently ranked as the third leading cause of death in the United States, just behind heart disease and cancer, as a cause of death for older people. AD is one of the greatest economical threat acknowledged by most developed countries. Research shows that the expenditure due to AD will be 7 billion USD in 2030 only in the United States [1] including care givers. At present, there is no cure for AD, and this incidence is higher in developed countries, which correlates with the proportion of senior citizens [10, 11]. According to Alzheimer Disease International, nearly 44 million people have Alzheimer's disease or a related dementia at a worldwide level [12], and the number of affected people around the globe would be 65.7 million by 2030 [13]. Being an overpopulated country and most people living in rural areas, there is a very little concern about AD in Bangladesh among general people.

There are some screening tools used around the world that include standard questionnaire to detect the probabilities of the early-onset of AD [1, 14]. Some world-wide such screening tools are Mini-Mental State Examination (MMSE), Geriatric Depression Scale (GDS), and ABC Dementia Scale (ABC-DS) [14]. Most of these could be used as primary screening tool. However, in Bangladesh, most of the mass people are not even at the stage of acknowledging AD as a disease.

The World Factbook 2011 (published by the US Central Intelligence Agency) states that health expenditure in Bangladesh stands at 3.4 per cent of GDP (2009). The density of physicians stands at 0.295 per 1,000 head of population and the density of hospital beds is 0.4 per 1,000 head of population. Around 40 percent of the total population live below the poverty line and there are over 7 million people over the age of 65. These facts

indicated that Bangladesh has no to poor facilities to deal with any chronical diseases such as dementia.

According to World Health Organization (WHO) Global Dementia Observatory Provisional Country Profile 2017, for every 100K populations, available number of neurologists is 0.09 with no geriatricians, no long-term care facilities, no adult day centres, and no outpatient social care centres in Bangladesh. The same report says that there is an existence of a dementia representative within the ministry with no integrated dementia plan and no available guidance for health and social care staff to manage dementia risk. However, there are a few non-government organization (NGO) making some trivial impact in dementia such as Sir William Beveridge Foundation and SAJIDA Home Care.

Sir William Beveridge Foundation has one unit "Dementia Bangladesh" centred on providing dementia care training for key staff by Alzheimer's Associations in Australia as well as by their experienced tutors in Bangladesh. They held their first International Dementia Conference in Dhaka, Bangladesh in 2014 to create awareness on the Challenges of an Ageing Population for a Developing Country, which did not result dementia recognized and addressed properly. On the other hand, SAJIDA Home Care is providing home-based health care to 36 patients in various locations of Dhaka city with 62 caregivers, 23 among them having training on dementia from Bangladesh Dementia Task Force–BDTF is a social media based organization that promotes Dementia issues in Bangladesh by raising awareness.

There are some research going on in Bangladesh, most of which being confined in small trials, or reviewing the overall situation from a certain organization [15] and molecular biology [16]. Comparing to the awareness and concern regarding AD among developed countries in the world and Bangladesh, these approaches are far from sufficient given that we do not have a clear picture of our gross economical loss due to this disease. We still need to make people in acknowledging AD as a severe threat and making us equipped to deal with it.

Furthermore, neurological examinations are crucial in the differential diagnosis of AD [17], and the diagnosis includes based on the person's medical history, history from relatives, and behavioral observations [18, 19]. The assessment of the disease includes interviews with family members along with the patients. Since a person with AD is commonly unaware of his own deficits; hence, caregiver from family commonly provides assistance. Family members can be supplied with important information on the daily living abilities, as well as on the decrease of the person's mental function from the caregivers over time [20, 21]. Nonphysician care providers can help to increase detection of cognitive impairment within their scope of practice and training [22]. Sometimes, families also have difficulties in the detection of initial symptoms of AD and may not communicate accurate information to a physician [23]. Hence, having a specifically defined scheme for the caregivers is crucial to this project.

Our government has a very humane policy for elderly people that children can be subjected to punishments for avoiding caregiving their parents (The Parent's Care Act, 2013). However, there is high probability that caregiving to one of the parents with AD without proper training is beyond plausibility. As most of our population has little to no understanding of AD, parent- children relationship has a high probability of giving rise to emotional agitation, possibly social anxiety and stress. Using modern technology in dementia care people can be trained to use care delivery system and social interaction [24], which has a potential to improve this situation. Our project can provide people with generic training from efficient trainers via either Artificial Neural Network, or Human-machine Interface.

Proposed Approach

In this project we propose a detailed survey on prevalence of AD, specifically, age, sex, area, and how people treat AD. The next step would be observing healthcare facilities (both government and nongovernment organizations) to find the exact number of people with basic training or, expertise to treat AD. There are a number of virtual sources where we can find appropriate questioners to find out symptoms of early onset of AD, most of which are still ongoing research projects, or waiting for clinical trials. However, Mini-Mental State Examination (MMSE), Geriatric Depression Scale (GDS), and ABC Dementia Scale (ABC-DS) [14] are available for the standard questionnaire for AD screening, which we can use as motivation to develop a standard set of questionnaire appropriate in Bangladesh. We intend to use those to build a virtual platform through ICT to develop awareness of AD among mass population in Bangladesh. As mentioned in "objective", this virtual platform will have the potential to direct affected individuals to trained caregivers.

The system will have a cloud based AD screening, monitoring, and training application. The main users of this system are i) people of developing countries having no or limited medical services and professionals available and ii) physicians and AD caregivers living in different location who can help the patients with screening as well as maintenance using an automated system. Government healthcare departments, government hospitals, private hospitals and clinics, NGOs, private healthcare organizations, and internet and mobile phone service providers are the stakeholders of this system. There are two different features; one for potential patients in screening process and the other for caregivers (as shown in Fig. 1). The caregivers could be a family member or, healthcare personnel.

The general users will access the system via smartphone App after registering for the first time with assigned unique User ID and password after registration. The system will assess the person's condition based on a set of questionnaires. The nearest family members will also have to respond to some questions. Then the system will upload the -

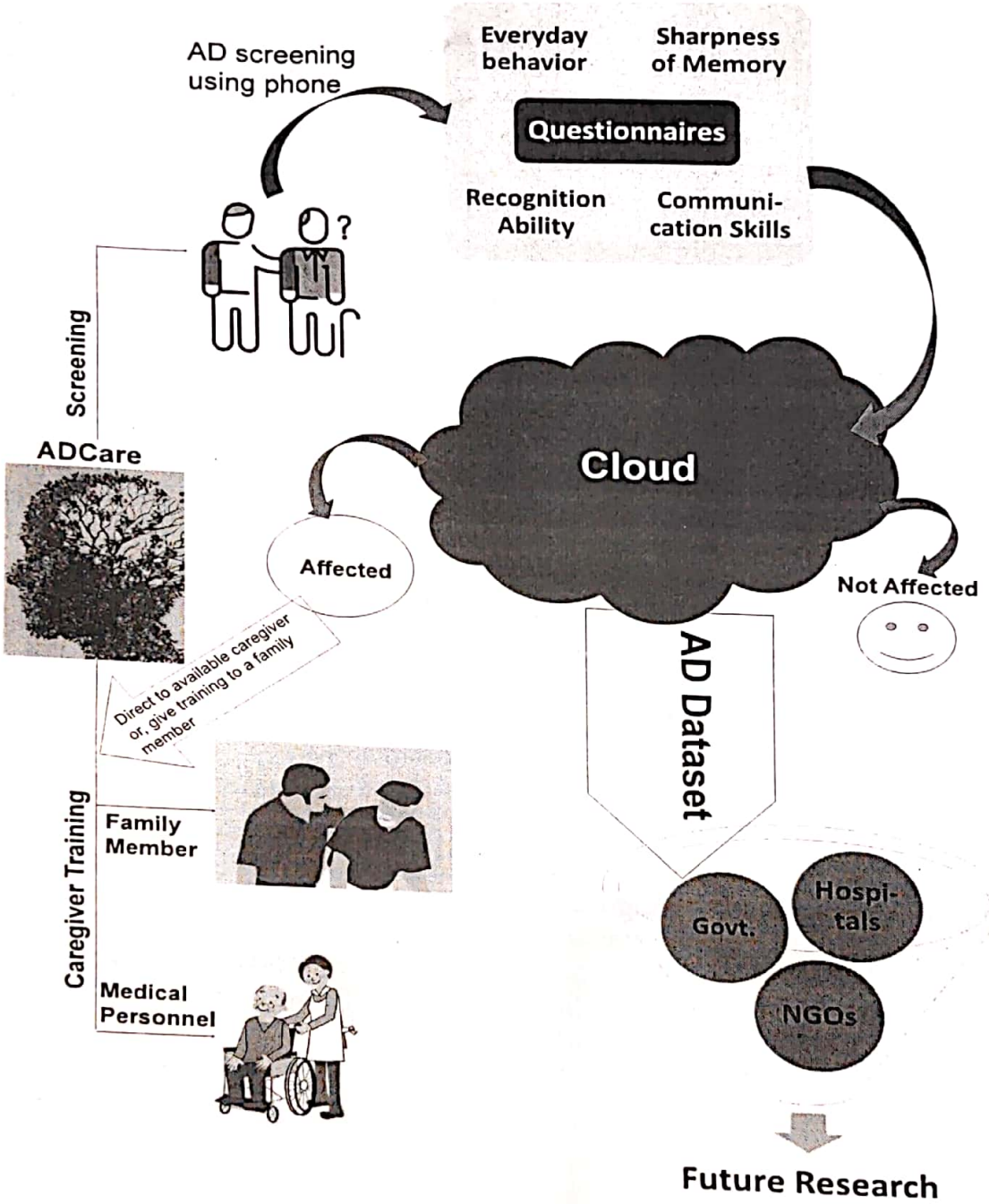

Fig. 1: Proposed approach of basic ADCare system to provide screening and caregiver training.

files to the cloud. The responses will be stored in our database in the patient file under a unique User ID of that particular individual. The samples will be sent to the Feed forward Back-propagation based Artificial Neural Network classifier for classification of the probability of AD. Now, if the classifier classifies the responses as positive signs of AD, then the system sends the user a message said "AD symptoms identified. You need to consult a trained caregiver." The system will show the patient a list of AD caregivers and healthcare centers or, doctors with their location maps so that the patient can find out the nearest place to get help. Our application provides a list of remotely referable healthcare centers, doctors, and caregivers. The app will direct family members to caregivers who can train them to deal with AD.

Another feature of the system will connect with healthcare personals to assess their level of competence to deal with AD. They will receive basic training on AD from the cloud based system. The system will keep record of trained caregivers to connect them to potential patients.

Procurement Plan:

What	Why	When	Amount to be spend
People	To collect data	Within two weeks of project offering	300000
Web hosting	Cloud Space	Within six months of project offering	100000

Required Budget (including breakdowns and shared cost):

SL	Item Description	Amount in bdt
1	Data collection, Data Analysis, and building database for AD situational resources in Bangladesh (Honorarium of Researcher and Supervisor, and required Resources)	300000

2	System Requirement Research Analysis (honorarium of Researcher and Supervisor, and required Resources)	100000
3	Research on existing systems, identifying AD screening approach, and validation with Bangladesh context	250000
4	Research on development of AD detecting Application (Honorarium of Researcher and Supervisor and required Resources)	200000
5	Mobile apps, backend, frontend development for AD screening application (App development in android and IOS, Database, Testing)	200000
6	Research on Design and Development of training module	100000
7	Online training module development for caregiver and integrating to the system (Integration and testing)	250000
8	Web hosting	30000
9	Content Development	200000
10	Conference and journal publications	50000
11	Dissemination through Conference, Publications, Newspapers, Facebook etc.	50000
12	Training and feedback workshop for usability and awareness for users and caregivers	100000
13	Operating Expense and Audit	50000
14	Final report of the project	50000
15	Contingency and Miscellaneous	10000
	Total	1940000

Impact and Future Outcome

The primary goal of this project is to increase awareness among people about AD and gather the exact situation of AD in Bangladesh including prevalence and existing facilities like other countries in the world. Awareness will eventually lead to acknowledging AD as a severe threat to us and make our country equipped to deal with AD. We can also use ICT as a platform to train people even in remote areas with minimum cost. This will give us a group of generic caregivers who can train family members of AD patients to take care of them. Researchwise, this project will produce at least two conference papers and one, or two journal articles. Furthermore, we will have a big data set to study that can reveal other possible research opportunities at time.

References

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