

## CareD: Non-Pharmacological Assistance for Dementia Patients

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### Abstract

**BACKGROUND:** Dementia is a common form of Alzheimer disease which is affecting the quality of older adults' life. Non-drug treatment such as cognitive therapies are more beneficial for such patients. These days, mobile applications are providing tremendous opportunities for aiding the medicinal treatment.

**OBJECTIVES:** This paper presents CareD – a mobile application based solution for dementia patients and their caregivers. Unlike, other available mobile applications, CareD provide a single resolution for maximum dementia related complications. The main objective of this application is to improve the quality of life of dementia patients and facilitate their caregivers. CareD also aims at providing native language support i.e. Urdu to the people of Pakistan.

**METHODS:** CareD comprises of various modules including cognitive therapy sessions, patient tracking, reminders, healthy living to aid dementia patients in their everyday activities. Experimental study involving dementia patients and their caregivers has been carried out to evaluate the usability and effectiveness of this application.

**RESULTS:** Twenty patients were included in the study. Results showed that CareD is very effective and helpful in decreasing the disease progression as well as in relieving the burden of caregivers.

**CONCLUSION:** CareD has been found to be a useful and efficient solution for dementia patients. It was observed that utilization of mobile application was progressively successful in reducing the stress of both; patients and their caregivers. The use of native language Urdu made the application more learnable for older adults and improved its acceptance.

**Keywords:** Alzheimer's disease, cognitive therapies, Dementia, Mobile App for Older Adults.

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### 1. Introduction

A neurological disorder or mental disorder is a syndrome characterized by a clinically significant disturbance in an individual's cognitive, emotion regulation, or behaviour that reflects a dysfunction in the psychological, biological, or developmental process underlying mental functioning [1][2]. Neurological disorders are said to be the fifth leading cause of death globally. Alzheimer's disease including Dementia are the most prevalent neurological disorders [3]. Dementia is a cognitive impairment that leads to gradual declining in mental abilities such as memory, language,

orientation, and judgment, and physical functioning, causing the one to be dependent on others [4]. It is a progressive disorder which involves degeneration and death of brain cells (neurons). These cells send messages between different parts of the brain and also to other parts of the body. This severe disease interferes with a person's daily life and activities by affecting the cognitive skills which ultimately lead to severe memory impairment. As a result patient becomes completely dependent on others for everyday activities. Alzheimer's Disease (AD) is basically the most common cause of Dementia in older adults that accounts for two third of the Dementia cases [5].

Dementia has been spreading rapidly and around 50 million people worldwide are living with dementia. This

number is expected to be than three times by the mid of this century [5]. According to a recent research [6], AD is the sixth leading cause of death in the US with around 5.7 million dementia patients. This number looks scary for a country where ample population-based study on neurological diseases has been conducted for the last several decades as compared to underdeveloped countries. This rapidly growing disease is indeed a big challenge for underdeveloped countries where ample attention is not paid to dementia on governmental levels as well as on individual levels. Lack of required attention by governments is the barrier in providing economical or subsidized treatment for this disease and thus, creating awareness among the public in large. According to the Alzheimer's Pakistan, around one million Pakistanis are affected by AD [6].

The most important aspect of AD is the increased amount of cost involved in order to cope up with it. The total estimated cost to take care for patients of dementia and Alzheimer seems to be very expensive. As per the World Alzheimer Report 2018, the worldwide total estimated cost incurred in 2018 for this sake was \$1 trillion which is projected to become double by 2030 [5]. Only in the US, the cost for this purpose has hit around one-third of the total current world-wide cost. The major chunk of this cost is being incurred in developed countries. Due to the low level of awareness, people of underdeveloped countries see this disease as part of aging and as a non-curable disease and eventually avoids its curing. Moreover, the poor financial conditions of people of underdeveloped countries make the situation worse. An individual with per capita income of \$1500 cannot afford to pay for the cure of dementia [7]. Ultimately, some of them prefer to accept this disease as part of their destiny while some choose to seek the help of their family members. A very small number of patients move to qualified dementia consultants. This approach to treating dementia is not good. Nobody can take care of a dementia patient as a consultant can do. As a result, in most cases, these untrained caregivers complicate or worsen the AD cases.

There are various drug and non-drug treatments available for AD that aims at stopping and delaying the cognitive disorders and help one to stay self-dependent. Pharmacological treatments may lead to side effects such as sedation while non-pharmacological alternatives are more effective without undesirable effects.[8] Good AD consultants use non-pharmacological cures first to treat an AD Patient and resort to pharmacological treatments when the former do not yield desired result [9]. The non-drug treatments include various Cognitive, Physical, Emotional and Social Stimulation therapies that can be provided by the health care unit[10]. These non-drug therapies benefits individuals with mild to moderate Dementia and they play a significant role in improving cognitive functionalities; Problem-tackling abilities, Memory Loss, Language problems etc. Cognitive Stimulation Therapy (CST) is considered to be non-pharmacological treatment that benefits the individual on cognitive functioning, improve the quality of life and also the quality of care giving [11]. CST

is recommended to be offered to the people with mild to moderate stage of Dementia [5].

By considering all of these factors, there is a high need of a systematic model that provides easy support to the care providers as well as the care recipients, and that also overcome the mounting health-care cost. The study shows that there is a potential use of smart phone applications that facilitates in awareness, prevention and treatment of the mental illness [12]. Mobile health applications are a promising intervention for such diseases [13]. Numerous mobile applications have been developed to deal with the wide range of health related concerns. However, more effort is required to explore the effective IT based solutions to facilitate Dementia patients and their care givers. Also, economical non-drug remedies such as therapies can be conducted more easily. One of the challenges in developing such a solution is that the users are not only older adults but their learning capability has been limited because of this disease. Hence, the solution should be simple and usable to be accepted by the patients. There are various researches [14][15] which show that people with age of 60 or above are more prone to this disease. Their capabilities in using technology must be developed so they can get benefit from technological solutions [9].

Existing mobile based solutions has two major limitations. First, there are separate Apps for every problem so the patient is required to download a dozen of Apps to fulfil his/her requirements. Second, none of these Apps was developed for people of Pakistan and hence lack the element of localization. A perfect example of it is that they are available in only English language. With the best of our knowledge, no application for dementia patients is available in Urdu language.

This paper presents CareD – A mobile phone application which serves as a non-pharmacological assistance for dementia patients. It addresses the aforementioned limitations and offers an integrated and comprehensive package specifically for Dementia patients and generally for Alzheimer's patients in Pakistan. CareD provides cognitive training through activities to descend the progress of Alzheimer's-connected debilitations and to manage behavioural manifestation, which can be treated with a blend of changes in environment, medication and psychotherapy. Also, it is the only solution developed for Pakistan that aims at serving Alzheimer's patients in the native language i.e. Urdu. This will add to its ease of use and enhance its local usage. This user friendly app offers multiple features in a single platform to serve Alzheimer patients. It offers activities to support cognitive skills of patients by helping them to remember events and stay connected with friends. It gives features like setting reminders for medication, prayers, meeting, events and other daily chores that not only make the life of the patient trouble-free but also make him self-dependent. Moreover, this app facilitates caregiver to have a check on the patients' progress on various activities through progress report of the patient. One of the most prominent features of this app is that it collaborates with Google maps and provide geo-tracking for patients. This gives regular updates to caregivers about the current location of patients

and sends immediate alerts to them when patients do not reach to scheduled appointments. Throughout the development process of CareD, multiple experimental studies have been carried out to evaluate the usability and effectiveness of the application. Questionnaire survey has also been conducted from the caregiver to get their reviews. The contribution of this research can be summarized as follows:

- (1) The paper presents a comprehensive overview and comparison of existing mobile applications developed for Alzheimer's and/or dementia patients
- (2) This research proposes and implements a novel solution CareD, an easy to use mobile application that provides a single platform for both caregivers and Alzheimer's and/or dementia patients
- (3) Experimental evaluation and usability analysis of CareD is conducted involving patients and their caregivers.

This paper is organized in 5 sections. In second section, we provide a comprehensive analysis of existing technological solutions, especially mobile applications developed for Alzheimer's and dementia patients. Third section describes our proposed solution CareD. Experimental study plan and evaluation is discussed in section four, while section five concludes the paper with discussion and future research direction.

## 2. Related Work

Many research studies asserted that smart phones and tablets are the potential solutions to satisfy the needs of individuals with dementia[16][17][18]. They have the capability to assist them in dealing with this disease. The subjective exploratory research [19] was performed to discover the help of touchscreen gadgets (e.g., smart phones and tablets) for people with dementia. During the sessions, it was seen that individuals with dementia have the ability of adapting new aptitudes through a few training sessions and have capability in grasping new advancements. It is likewise expected that self-administration capacities among dementia sufferers can increment by utilizing such applications. By 2017, above 325,000 such apps were available for smartphone users [12]. These apps are available in android, iOS and other operating system. This section presents a brief overview of popular applications designed for Alzheimer or dementia patients.

Mind Mate\* and Lumosity, are the mobile applications that offer mini mind game challenges to improve the mental health of their users. These games deal with the four cognitive domains i.e. problem solving, memory, speed and attention. These apps generate weekly

\* <https://www.mindmate-app.com/>

progress reports of the patient that help caregivers to monitor their patients. Additionally, Mind Mate also offers features like exercise tutorials for body workouts and suggest nutrition advices as well as healthy recipes for mental well-being. Lumosity is available in both android and iOS but Mind Mate is only available in iOS, which makes its limits its utilization. Brain Challenge is an android application that also offers different type of mind games and activities that keeps the user involved and active. These games are designed to stimulate user's mind which helps in reducing disease progression.

As the research shows that the care givers faced difficulty due to their patients at certain time periods of a day i.e. late in the afternoon or early evenings[20]. There are several moods that the patient tends to go through during that time. DementiAssist App helps caregivers in identifying the mood of their patient and to provide assistance about how to take care and cope with them during that period.

Timeless App helps patients stay aware and remember what is happening in the family. This is done through images of family events and recording contacts with a photo of the person which helps in remembering and recognizing people. The pictures can be updated by patient's family along with the person's name and relationship. Secondly, it also provides a feature of clicking the person image to know their name and relation with them which is handled through Artificial Intelligence, like Facebook tagging.

Table 1. A comparison of the features of the existing applications and the proposed application CareD

Features	Mind Game	Location Tracking	Prayer	Contacts	Healthy Diet	Workouts	Reminders	To-do-List
Apps								
Mind Mate	✓	X	X	X	✓	✓	✓	✓
Dementia Assist	X	X	X	X	X	X	X	X
Brain Challenge	✓	X	X	X	X	X	X	X
Timeless	X	X	X	✓	X	X	✓	✓
Lumosity Mobile	✓	X	X	X	X	X	X	X
It's Done	X	X	X	X	X	X	✓	✓
CareD	✓	✓	✓	✓	✓	✓	✓	✓

It's Done is a checklist App that helps in day to day life chores. The patient or their families must create the to-do-list they need to follow or they can set reminders of the task they need to perform and once that task is done the patient will check that task as done. The only drawback is that it is a paid app, so users who can afford, can use it.

There are many such apps that objectives just a single certain feature for Alzheimer and provide it's cure; like

either they are for reminder, for alarms, for notes or for mind games or for brain exercises. The major benefit of CareD is that it brings all these individual features into one platform so that patients do not have to download multiple Apps for their use, they will have to just download one single App for all their problems. Moreover, it is available in both English and native language i.e. Urdu for the people of Pakistan. The table 1 shows the comparison among different applications for Alzheimer's.

### 3. CareD – The Proposed Solution

Number of studies suggests that Dementia is gradually increasing in Pakistan and there is a lack of specialist dealing with such patients. Moreover, public awareness of dementia is low leading to late diagnosis [21]. Considering the needs of Dementia patients, specifically in Pakistan, this paper presents CareD, a consolidated and localized smart phone application based on android platform. CareD, is proposed and implemented with the aim to spread awareness about Alzheimer, including Dementia, and provides therapies for its remedy. It is regarded as the non-drug tool which provides a single platform that merges the bunch of activities and cognitive therapy sessions for AD patients. The main focus of these therapies is to improve cognitive functions by involving the patients in various activities. The activities include problem solving, thinking, memory and concentration. CareD, is not only limited to activities, but also has modules to help patients in their everyday tasks. The reminder module prompts for daily exercise, doctor visits and medicine time. Similarly, position tracking module helps the patient to safely return home and informs the caregiver of the patients' current location. Likewise, the prayer module assists in learning and revising daily prayers. In addition to these features, CareD provides a user friendly interface in both English and native language i.e. Urdu. It will increase the user base with a broad margin and gives CareD a competitive edge over other similar mobile applications.

The targeted users for the applications are the people suffering from AD and their caregivers. AD patients can take remedies in terms of therapies and can carry out other activities for improving their mental health, whereas the care-givers can assign tasks to their patients and also monitor their activities and progress. The key benefit of CareD is that it helps the one who suffered with AD by providing therapies at home, because most of the elderly people are reluctant to visit to the therapist. It also decreases the burden of the care-giver by automating the care giving process. It facilitates to enhance the quality of life by using information technology and can be considered as cost-effective and most feasible solution for Alzheimer's society. CareD comprises of the various modules that intended to provide better mental health to the community dwelling. These modules include: cognitive therapy sessions, tracking patients, reminding technology and healthy living.

### 3.1. Methodology

This study has been carried out by two primary approaches.

1. The comprehensive analysis of existing applications for dementia health care and finding out potential limitations.
2. Development of an application which not only assists the caregivers of the dementia patients but also aids in slowing down the declining process.

After carefully execution of the development process, CareD has been tested and verified with the caregivers.

### 3.2. Cognitive Therapy Sessions

The App has several cognitive therapies that are based on mind games, aimed at utilizing and exercising the brain. These games help the patients in stimulating their brains which results in slowing down the progression of disease[22]. The four cognitive domains that are targeted in these games are: Problem Solving, Attention, Speed and Memory. At the end of each game, progress report is generated to monitor the performance of patient. The progress report is available to both patient and caregiver.

#### a. Problem Solving

Most of the Dementia patients are not able to respond actively as their understanding and problem solving skills have been affected by the disease. To improve the capability of thinking, a simple problem solving activity has been included in CareD. The activity is designed in the form of a number drill game.

#### b. Speed

Speed is a cognitive ability that measures how quickly user performs the task. This activity will help the patients to boost their ability to respond quickly. The quiz game is designed to assess and improve the mental alertness.

#### c. Attention

People suffering from Alzheimer's are usually not able to recognize the task and hence could not pay attention to it. This activity is designed to improve the ability to focus on things by paying more attention. It will test and improve patient's selective concentration skills.

#### d. Memory

Constant mental activity leads to reduction in Dementia [22]. Therefore, along with other activities, Memory game is incorporated in CareD to enhance the mental activity. Memory game encourages patient mind to do mental task for example, solve puzzle games or memorize the objects and place them in the same order which will helps in retaining the memory. The feedback report provided at the end of each session keep the patient motivated in improving



the score, which in turn helps in improving the mental activity.

### 3.3. Tracking Patients

Due to forgetfulness, the AD patient often tends to forget the locations and their whereabouts hence resulting in worried caregivers. The location tracking feature helps to track patient's location when they leave the home premises. If the patient forgets the returning route to reach home then the CareD application will guide them, with easy to understand navigation instructions in native language, which is Urdu. The caregiver can also track the location of the patient anytime.

### 3.4. Reminding Module

From the initial stage of the AD, the patient suffers from the memory impairments that leads to worries on everyday life functioning. To accommodate with this situation, our application offers reminding module that provides the following features:

- (1) Caregiver can set the reminder such as taking medicine or food, daily exercise, reading books or newspapers and many more daily life chores. The patients can be reminded by push notification received by their smart phones.
- (2) They can also maintain the to-do list for the daily task by the mobile application. It helps them to remember the task they have to perform.
- (3) AD patient often feels difficulty in memorizing the Salah or other prayers. Our application includes different prayers in audio format to which they can listen as many times as they want in order to remember it.

### 3.5. Healthy Living

Regular physical exercises and proper diet are beneficial for mental and physical health. Aerobic exercise is one of the feasible and well perceived mediation for older adults with AD [23]. Our application provides video tutorials for different workouts, aerobic exercises or yoga poses. It also suggests tips for healthy diet and recommends various diet plans.

## 4. Experiments

To test the usability [24] of CareD among the targeted age group, an experimental study [25] was designed and carried out using the direct observation of user in addition to the questionnaire provided to them. The experimental study is aimed at testing the usability and effectiveness of an application. The experiment was conducted at two well-known hospitals of Karachi in which patient and caregivers

tested the application. The different steps of the experiment are discussed below:

### 4.1. Experiment Subjects

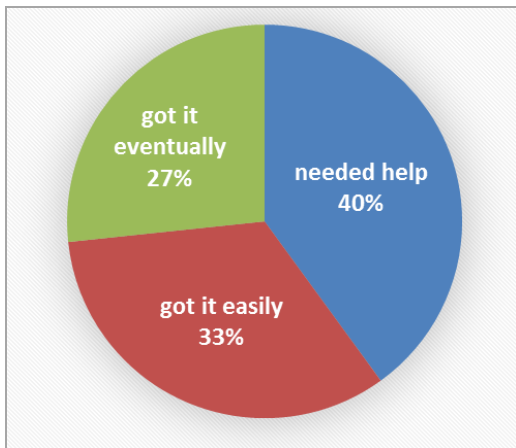
The old age people suffering from Alzheimer's and their care givers were subjected for the experimental evaluation of the CareD. Different age groups of old age with different stages of the Alzheimer's i.e. mild and moderate has been targeted. We designed different task sets and assign it to ten patients. We have logged the time, taken by them to complete the task to evaluate their learnability. By this experiment, it was observed that the time taken by the patient with mild stage is less as compare to moderate. The tasks that are easy to understand like setting reminders, adding notes and playing simple activities are less time taken by both the stages of patient. Some tasks which include activities/game such as memory game, quiz, number drill, color splash and location tracking were difficult to understand and took more time to complete. The table 2 shows the time taken by each patient of different stages in performing each task.

Table 2. Task Completion Rate

	TASK	STAGE	Time taken to learn the task for the first time and practice at least once
1	Reminder	Mild	2 min
		Moderate	3.5 min
2	Add Notes	Mild	2 min
		Moderate	3 min
3	Memory Game and Number Drill	Mild	3 min
		Moderate	4 min
4	Color Splash	Mild	3
		Moderate	4 min
5	Share Location	Mild	3 min
		Moderate	5 min
6	Quiz Game	Mild	5 min
		Moderate	5.5 min
7	Prayer Healthy Diet Workout	Mild	3 min
		Moderate	4 min

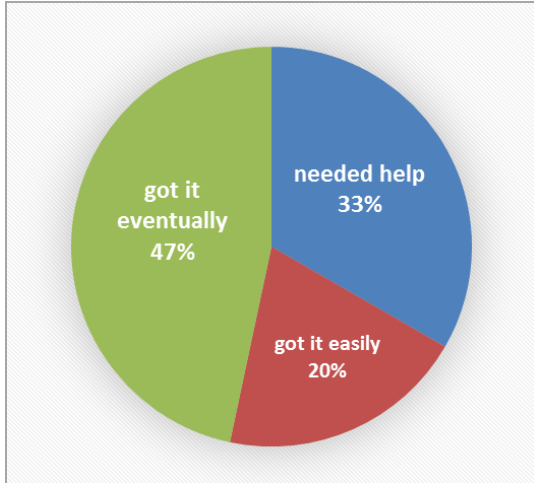
Figure 1, 2, 3 and 4 show the graphs that identify the learnability of each task assigned to the patient. The same task was subjected to both mild and moderate stages of patients. Fifteen patients of mild stage were assigned the task of using the feature of tools in which both the reminder and daily task feature are present. While the patients were using the application, the observation was carried out. Out of fifteen patients, six patients sought help in using the feature often, five patients got the feature easily whereas

four patients got it eventually with some time to time guidance. Figure 1 shows the overall percentage.



**Figure 1. Mild stage (Tools)**

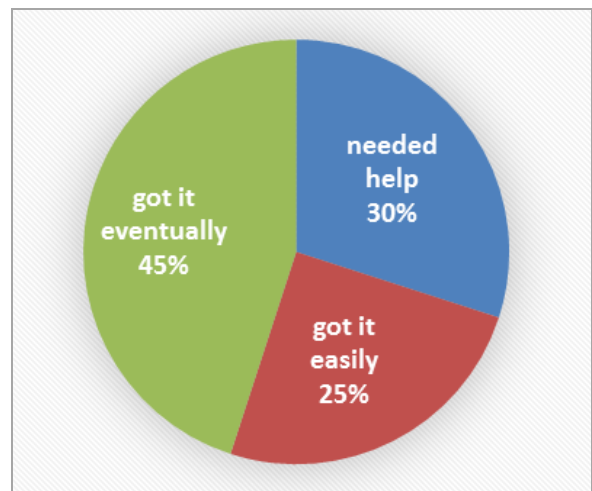
The figure 2 is for patients with moderate stage. Fifteen patients having moderate stage of Alzheimer were observed by assigning the task to use the feature of reminder and daily task. Out of fifteen patients only three patients got the task easily whereas seven patients got the use of feature eventually and five patients needed help in re-understanding the task. Figure 2 shows the overall percentage.



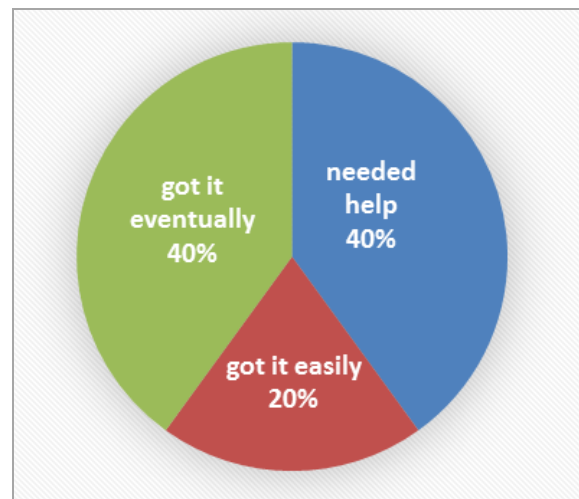
**Figure 2. Moderate stage (Tools)**

The Figures 3 displays the results of activities (mind games) that were assigned to mild stage patients. Twenty patients were assigned individually to perform different mind game from the application. Each patient was then observed based on the guidance given before the task was assigned to them. Out of twenty patients, five patients performed the task easily after single guidance whereas nine patients understand the game eventually and six patients required help multiple times to understand the task. Figure 3 shows the overall percentage.

The Figure 4 shows the performance of patients suffering from moderate stage of Alzheimer’s. As patients suffering from moderate stage tend to be more vulnerable and forgetful hence the chart shows the number of patients that got the task easily and those who needed help. Twenty patients with moderate stage were assigned an individual game to play so that their activeness of brain and their learnability of application can be tested and observed. Out of twenty patients, only four patients got the task easily whereas eight patients required help multiple times to understand. Similarly, eight patients got the task eventually when playing game was assigned to them as task. Figure 4 shows the overall percentage.



**Figure 3. Mild stage (Activities)**



**Figure 4. Moderate stage (Activities)**

#### 4.2. Effectiveness of the task

The effectiveness of the CareD is measured by calculating the amount of time required by patients to reach the desired option after being familiar with the application. Figure 5 depicts the effectiveness of each task for patients of both the

stages. Figure 5 shows the time (in seconds) taken by patients to find the particular option in the application. The patients with the mild stage Dementia took comparatively less time than moderate level Dementia patients. For some of the features of applications both mild and moderate stage patients took equal time. It was also observed that use of native language, Urdu, improved the understandability and effectiveness of CareD.

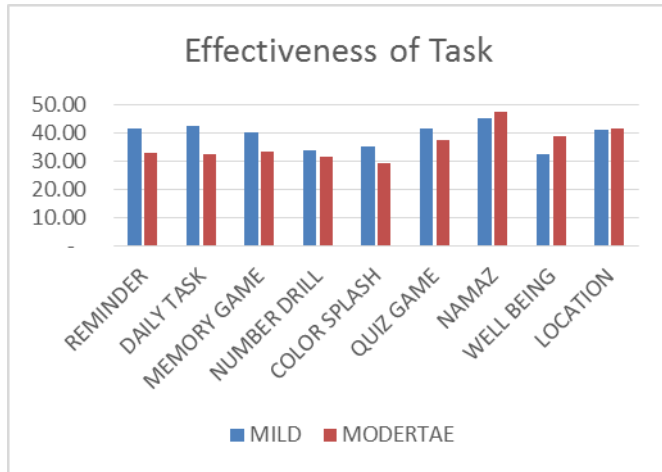


Figure 5. Effectiveness of the task

### 4.3. User Interface Design

The user interface was evaluated by both the patients and the caregiver. Questionnaire survey [26] has been conducted to evaluate the user’s satisfaction level. The questionnaire filled by caregiver was from the perspective of the application learnability and understandability that they have observed in the patient after using the application.

Table 3: Questionnaire for caregiver

LEARNABILITY	FUNCTIONALITY
1 I found that even after taking proper training the patient is finding difficulty in using the application.	1 I found improvement in patient memory after performing mind activities.
2 I felt that the learning of the application takes time.	2 I found remind me feature very helpful.
3 I found the feedback given by app is sufficient.	3 I found the well-being feature very helpful as a caregiver in taking care of my patient health.
4 The use of terms throughout the system is consistent.	4 I think that the Prayer feature helps the patient in remembering their daily prayers.
5 I think the terminology is always intuitive.	5 I felt the progress feature is helpful to doctor as well as caregiver in evaluating patients’ progress.
	6 I think CareD is beneficial in tracking patients’ overall record.
	7 As a caregiver I found the CareD application useful.

The results gathered from the caregiver’s questionnaire were mostly positive. Table 3 shows the questions that have been asked from caregivers to measure learnability and functionality of the application.

Figure 6 shows the graph of the responses that has been given by the caregivers. The results clearly mark the helpfulness of the CareD interface as around 80% of the caregivers faced no difficulty in learning the terms it uses and understanding the feedback responses it provides. The figure also depicts the efficacy of CareD since almost 80% caregivers were satisfied with the functionality it provides.

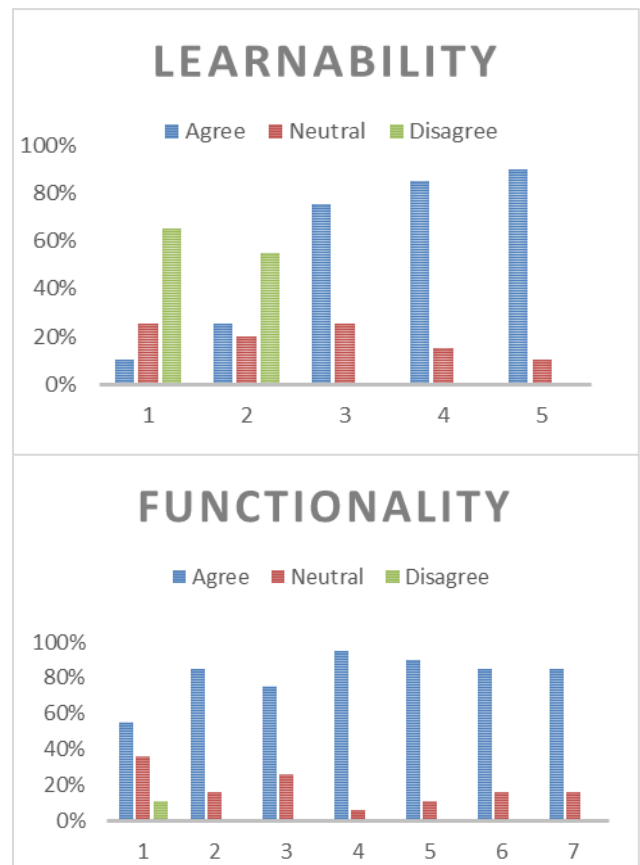


Figure 6. Graph for Learnability and Understandability

### 5. Conclusion and Future Enhancement

CareD is an effort in creating awareness among people about the Alzheimer's disease and Dementia and its preventive measures. It is aimed at facilitating and improving the quality of life of the Dementia patients and their caregivers. CareD provides multiple cognitive therapies, Patient Tracking, Reminders and other activities into a single platform that collectively can improve the quality of life of Alzheimer's disease and Dementia patient. Furthermore, the process of care giving has been automated which reduces the burden of the caregivers. Caregivers can easily track patient activities’ progress and location. Number of patients and their caregivers were recruited for

experimental study. The results showed that CareD was an effective solution and users were very comfortable and satisfied with the application. The use of native language, Urdu, helped older adults understand the application easily. We have also received the positive responses from the caregivers regarding CareD.

CareD can be improved in several ways. Currently, it is available for English and Urdu Languages however, more languages can be included. It is presently offered with android platform but we are looking forward for its cross platform version as a future endeavour. We also tend to add more activities in the form of games so that more cognitive training can be given to the patient.

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