

# PEAR: An approach for Person-Centred Care of Dementia Patients

Ashish Kumar<sup>1</sup>, Syin Chan<sup>2</sup>, Chiew Tong Lau<sup>3</sup>, and Maode Ma<sup>4</sup>

[ashish007@e.ntu.edu.sg](mailto:ashish007@e.ntu.edu.sg), [asschan@ntu.edu.sg](mailto:asschan@ntu.edu.sg), [asctlau@ntu.edu.sg](mailto:asctlau@ntu.edu.sg), [emdma@ntu.edu.sg](mailto:emdma@ntu.edu.sg)

<sup>1</sup>Joint NTU-UBC Research Centre for Excellence in Active Living for the Elderly

<sup>2,3</sup>School of Computer Science and Engineering

<sup>4</sup>School of Electrical and Electronics Engineering

Nanyang Technological University, Singapore - 639798

## Abstract

**Background:** With the exponential growth in the number of dementia patients, care facility faces unprecedented challenges. In one hand, we aim to provide better services employing the philosophy of Person-centered care, on the other hand, we face a severe scarcity of resources in terms of finance, time, and manpower. **Method:** Technology is our best resort to meet the ever-rising demands in this sector. PEAR is an application which tackles this problem by developing an end to end information technology infrastructure, based on the principle of Person-centered care. It is designed to be used in a care facility to mitigate the task of scheduling of activities. **Result:** Usually, the scheduling tasks are performed by caretakers which take lots of time, effort and are not very efficient. The app provides method to automatically schedule the task of each patients based on its preferences and physical constraints if any. **Conclusion:** Many a times a personal preference is neglected due to lack of manpower or efforts in mitigating the managing the personalized preferences. The app tries to solve the problem associated with the lack of personalized care in day-care facilities.

**Keyword:** Dementia, Person-Centred Care, Games for Dementia, Scheduling algorithm, App for Dementia

## **I. Introduction**

With a whopping, 47 million people affected worldwide [1] with dementia and 9.9 million new cases every year, the number of cases of dementia is estimated to almost triple by 2050 [2]. Dementia refers to a condition usually of a progressive and chronic nature where there is a severe decline in the mental ability of a person beyond normal ageing process. It affects memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement which makes it difficult for them to live a normal life [4]. They are at the high risk of falling, getting lost or elopement in some cases. If these symptoms are not controlled, the consequence can be dire and reduces the one's quality of life. Alzheimer's disease is the major cause of dementia and accounts for 60–70% of all the cases [5].

Dementia leads to physical and mental disabilities where constant support is required from family members and caretakers. This is overwhelming not only for the people who have it but also for their family members and caretakers. Many family resorts to the daycare facility which takes care of their daily need. But with the increasing cases of dementia, these facilities are crowded, and personalized help is not possible at the individual level. Lack of proper facility and use of personalized care. This problem is particularly server in developing countries with the limited resources where the number is expected to increase four times [3]. Usually, these countries also lack infrastructure and stigma attached to the mental health. The impact of dementia can be social, economic, psychological, and physical. Person-Centred Care (PCC) is an integrated approach for care of the dementia patients in the nursing and day care centres.

### *A. Person-centred Care (PCC)*

The Nursing and Midwifery Council (NMC) [6] code directs that nurse must treat people as an individual with respect and dignity. This aims at identification of one's physical and mental condition along with their preference and constraints. This is a better holistic approach in

dementia care, which differs from prevalent task-oriented and professional-driven approach and emphasises on individual needs [7].

There are 4 main core concepts which abide by this philosophy [8]

**Dignity and Respect:** This is a people-first approach where care staffs must understand that each individual has their own set of preferences, culture, belief, values and spiritual backgrounds. These preferences should be incorporated while planning and delivery of care services. They should always be treated with dignity and respect their privacy. **Information**

**Sharing:** This is the philosophy of complete and unbiased information sharing between family members and caretakers. Family members should receive timely and accurate information to effectively participate in decision-making and care. **Participation:** This implies that people with dementia and their family members participate in the decision-making at the level they choose. This helps in strengthening the relationship between family members and caretakers.

**Collaboration:** It aims to promote collaboration among caretakers, family members and dementia patients. This would aid in implementation and care plan for the dementia patients.

The aim of person-centred care is to establish and maintain good partnerships among caretakers, family members and the dementia patients to improve the quality of life and care for the people with the disease.

With the widespread use of smart devices, it has been found that the usage of smart devices would bring about convenience and greater functionality in medical practices. Employing the usage of smart devices would allow for better care and treatment of dementia patients. This is a better way of caring for dementia patients through person-centred care, where caretakers would provide dementia patients with the appropriate support and care that they require. Caretakers would also be able to pay more attention to the personable needs of the patients such as their habits, abilities, preferences, and interests. However, the biggest obstacle in ensuring such a method would be feasible is the lack of manpower due to the rising number of dementia patients.

Person-centred care would mean that caretakers would provide personalized care to the patients by discovering and getting to know better the individual with regards to their life experiences, relationships, beliefs and values. By doing so, the caretakers will be able to provide better care by effectively empowering, reassuring and nurturing the person with dementia. Though this treatment is effective in caring for the patients, the challenge lies in the lack of manpower to care for each and every individual patient.

### *B. Games for Dementia Patients*

In recent years, technology has been introduced to help improve the condition of dementia patients as well as recording data of patient's condition for analysis. With the ease of acquiring mobile tablets nowadays, many mobile applications are created to aid dementia. **Clevermind** is a mobile application that aids dementia patients in organizing their daily activities and events. It is an interactive application that interacts with the user and provides a user-friendly interface for easy use. The user interface is simple, big, and organized giving dementia ease of learning of application usage. With this application, dementia patients can keep track of their daily activities to prevent forgetting important events and can be occupied to stimulate brain activities.

## **II. PEAR: A Person-Centred Care Approach**

PEAR has been developed keeping in mind the philosophy of PCC. It takes into account of individual preference, medical condition, physical constraints and requirement of dementia care facility to generate set of activities personalized for each individual. It is flexible enough to modify, add or delete activity in case if need arises. The application has been developed to be used by a dementia-care centre. The stakeholder here are doctors, dementia patients, caretakers and supervisor. Each of these stakeholders has different role, views, and privilege in the application. For e.g. caretaker role is to gather important information related to medical history, preferences, physical constraints which directly affect the set of activities which will be most suitable for the patients. A

doctor can view profile of patients and can also suggest some activities based on their need. Supervisors are generally family members; their role is to provide the personal information about patients' like and dislike and suggestions.

The aim is to provide better care to the patients through the use of technology and to improve the patients condition through more efficient care and treatment. The main objective of the app can be summed as:

- Ensure that centre activities can be easily managed and recorded
- Ensure that centre activities can be easily accessed and viewed
- Encourage a paper-less environment with information stored on the device
- Reduce manpower required to manage centre activities

#### A. System Architecture

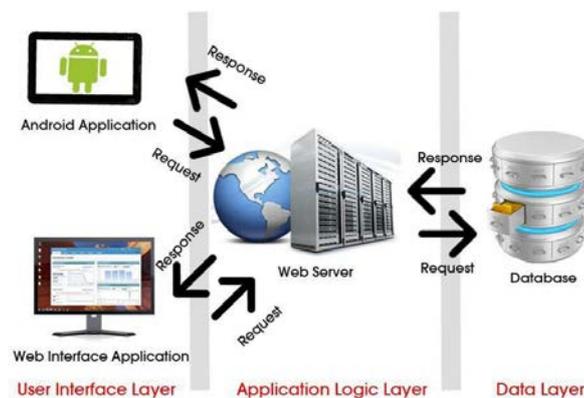


Fig. 1. PEAR System Architecture

It consists of three layers as shown in Fig. 1.

- User Interface Layer: This is the front-end of the system and provides two ways to communicate with the system. Android application can be used by supervisors, caregivers, and patients whereas Web interface can be used by doctors, therapists and IT system administrator. This also provides different views of the system based on the person's role and privileges.

- **Application Logic Layer:** It serves as the middle-ware between the android/web application and the database. It hosts the event-scheduling algorithm, which is the heart of the system. It also hosts the web and Android application.
- **Data Layer:** It is the storehouse for all the system specific information. It contains patients and event information.

### *B. Automated Patient Schedule Generation*

The purpose of schedule generator is to relieve the caretaker from manually generating the patient schedule for each day. In the real-world scenario different timetable scheduling has different objectives and constraints to fulfil. The schedule generator takes into consideration the following requirements when generating the patients schedule:

- Patients routine
- Patients preferences for the care centre activities
- Patients exclusion from a care centre activity or his/her routine
- Patients medical prescription
- Doctors recommendation for the patient
- Care centre activities and the availabilities

The schedule generator retrieves a list of compulsory centre activities sorted by fixed centre activity followed by flexible group centre activity and lastly flexible individual centre activity. Schedule generator can be programmed to run automatically every week.

C. Games for dementia care



Fig. 2. CatchTheNote: Main page

We also developed mobile game CatchTheNote for dementia patient, which can stimulates the brain and captures the interaction between elderly users and mobile game. The game can capture various parameter that defines behaviour during the game play. From the data captured during the gameplay, analysis has been carried out to monitor the conditions of dementia patient as shown in Fig. 4. These games can be suggested by doctors to be included in the daily schedule of a patients.

D. System features

PATIENT INFORMATION - JUSTIN LIM



**General Information Panel**

Patient ID : 1  
 First Name : Justin  
 Last Name : Lim  
 NRIC : [REDACTED]  
 Gender : Male  
 Address : [REDACTED]  
 Date of Birth : [REDACTED]  
 Handphone No.: [REDACTED]

Guardian Name : [REDACTED]  
 Guardian Contact No.: [REDACTED]  
 Guardian Email : [REDACTED]

**Action Panel**

**Actions**  
 Game Category Recommendation:

Game List Generation:  
 Auto Generation

MEDICAL CONDITION		Medical Condition Panel		
Type	Name	Reaction	Notes	
Allergy	Sore Eyes	Light	Beware!	
Dementia Type	Alzheimer disease			
Dementia Type	Dementia with Lewy bodies			

GAMES CATEGORIES								Game Category Allocation Panel	
Category	Comment	Reason	Duration (Minutes)	Days	Date Assigned	Prescribed	Approved		
Attention			30	30	08/02/2016	Yes	Yes	<input type="button" value="Edit"/>	<input type="button" value="View Report"/>
Hand-eye Coordination			30	30	08/02/2016	Yes	Yes	<input type="button" value="Edit"/>	<input type="button" value="View Report"/>
Speed	test		20	20	16/02/2016	Yes	No	<input type="button" value="Edit"/>	<input type="button" value="View Report"/>
Memory	test		20	20	16/02/2016	Yes	No	<input type="button" value="Edit"/>	<input type="button" value="View Report"/>

Fig. 3. Subject's profile, as seen on doctor's screen

Fig. 3. shows the profile of a patient as seen on web interface by a doctor. This is a one-stop point to see all the relevant information of patients. It contains multiple panels for general information, medical condition, game categories and action panel. The game panel contains parameters such as attention, speed, memory retention capability. This information is gathered from the game played by patients on the device. The doctor can view the report Fig. 4. for these parameters and suggest activity in the action panel, which will be included in the patients schedule from next time onward.



Fig. 4. Monthly Performance Chart of a patient

Fig. 5. is an example of list of the activity which has been generated automatically in accordance with all the constrains and recommendation.

The system has built-in intelligent algorithms to automatically customise daily activities for each patient. Notifications are automatically generated to alert caregivers and supervisors Detailed analysis of patient-game interactions. The system also has security features so that patients' private data is not compromised. The role based authentication method is used so that the information is not exposed to everybody. Only authorized access to the system is permitted and a log of all user activities is also maintained to ensure accountability. Updates of patient information require supervisors' approval to protect the systems integrity.

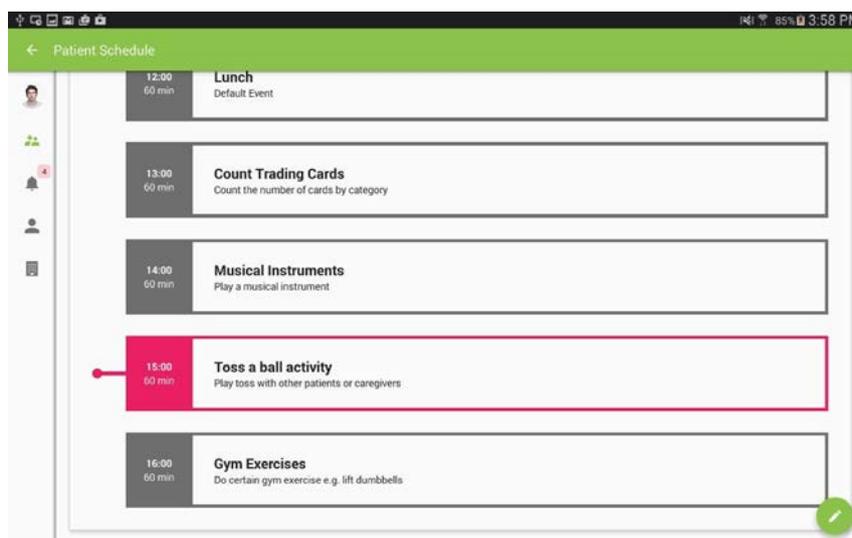


Fig. 5. Automatically generated schedule

### III. Conclusion

The purpose of the Pear application is to assist caregivers in providing better care for dementia patients and to make use of technology to allow for more efficient care methods. It provides a centralized platform for the care providers to manage the dementia patient in the Person-Centred Care approach. It also provides staff a more efficient way to work and to improve the patients' health condition by automatically planning a suitable timetable for the patient. It also makes the lives of caregivers easier by reducing their workload and in turn, they can provide better person-centred care for the dementia patients.

### Acknowledgement

This research is supported by the National Research Foundation, Prime Minister's Office, Singapore under its IDM Futures Funding Initiative.

### References

- [1] WHO, Dementia: Fact Sheet No. 362, Retrieved from [http:// www.who.int/ mediacentre/ factsheets/ fs362/en/](http://www.who.int/mediacentre/factsheets/fs362/en/), Accessed April 2015.

- [2] Larson EB, Yaffe K, Langa KM. New insights into the dementia epidemic. *New England Journal of Medicine*. 2013 Dec 12;369(24):2275-7.
- [3] Ferri CP, Prince M, Brayne C, Brodaty H, Fratiglioni L, Ganguli M, Hall K, Hasegawa K, Hendrie H, Huang Y, Jorm A. Global prevalence of dementia: a Delphi consensus study. *The lancet*. 2006 Jan 6;366(9503):2112-7.
- [4] Teri L, Larson EB, Reifler BV. Behavioral disturbance in dementia of the Alzheimer's type. *Journal of the American Geriatrics Society*. 1988 Jan 1;36(1):1-6.
- [5] McKhann GM, Knopman DS, Chertkow H, Hyman BT, Jack CR, Kawas CH, Klunk WE, Koroshetz WJ, Manly JJ, Mayeux R, Mohs RC. The diagnosis of dementia due to Alzheimers disease: Recommendations from the National Institute on Aging-Alzheimers Association workgroups on diagnostic guidelines for Alzheimer's disease. *Alzheimer's & dementia*. 2011 May 31;7(3):263-9.
- [6] Council NM. *The code: professional standards of practice and behaviour for nurses and midwives*. London: NMC. 2015.
- [7] Epp TD. Person-centred dementia care: A vision to be refined. *The Canadian Alzheimer Disease Review*. 2003 Apr;5(3):14-9.
- [8] Alzheimers Society of Canada. 2011. *Guidelines for Care: Person-centred care of people with dementia living in care homes*.



**Ashish Kumar** received his bachelor degree in computer science from Cochin University of Science & Technology in 2010. Now, he is pursuing PhD in computer science from Nanyang Technological University in Singapore. He is working in LILY lab, which is a NTU-UBC collaboration for the Excellence in Active Living for the Elderly. His research focuses on the design of computing technologies that help the elderly enjoy an active and independent lifestyle. His role is to develop inter-disciplinary research ideas to promote an active and independent lifestyle for the elderly. His research interest includes Wandering pattern in dementia, patterns recognition, deep learning, and artificial intelligence.



**Dr Syin Chan** graduated with first class honors in Electrical Engineering from the National University of Singapore in 1987 and obtained the PhD degree in Computer Science from the University of Kent at Canterbury, United Kingdom in 1993. She is currently Associate Professor in the School of Computer Engineering, Nanyang Technological University. Her research interests include multimedia information retrieval, web information extraction, ontology applications and multimedia understanding.



**Dr Chiew Tong Lau** received the B.Eng. degree from Lakehead University in 1983, and the M.A.Sc. and Ph.D. degrees in electrical engineering from the University of British Columbia in 1985 and 1990 respectively. He is currently an Associate Professor in the School of Computer Science and Engineering, Nanyang Technological University, Singapore. His research interests include wireless communications systems and signal processing.



**Dr. Maode Ma** received his Ph.D. degree in computer science from Hong Kong University of Science and Technology in 1999. Now, Dr. Ma is an Associate Professor in the School of Electrical and Electronic Engineering at Nanyang Technological University in Singapore. He has extensive research interests including network security and wireless networking. Dr. Ma has more than 320 international academic publications including over 150 journal papers and more than 170 conference papers. He currently serves as the Editor-in-Chief of International Journal of Computer and Communication Engineering and International Journal of Electronic Transport. He also serves as a Senior Editor or an Associate Editor for other 5 international academic journals. Dr. Ma is a Fellow of IET, a Senior Member of IEEE Communication Society and IEEE Education Society, and a Member of ACM. He is the Chair of the IEEE Education Society, Singapore Chapter and the Chair of the ACM, Singapore Chapter. He is serving as an IEEE Communication Society Distinguished Lecturer.