

Design Research Seminar Report

Designing cognitive and physical therapeutic activities for elderly living with Dementia.

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Declaration

I declare that this written document represents my ideas in my own words and where other' ideas or words have been included, I have adequately cited and referenced the original sources. I also declared that I have adhered to all principles of academic honesty and integrity and have not misrepresented or fabricated or falsified any idea/data/fact/source in my submission. I understand that any violation of the above will be cause for disciplinary action by the Institute and can also evoke penal action from the sources which have thus not been properly cited or from whom proper permission has not been taken when needed.

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Approval sheet

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Jury -

Guide -

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1. Abstract

Increased life expectancy and the population trends indicate a steady rise into elderly population. Demographic ageing is becoming a global phenomenon and correspondingly there is a rise in age related condition associated with impaired cognitive status such as dementia. [1] [2]As per the report by WHO with steady rise in ageing population, dementia is going to be an epidemic in coming decades. [3] Dementia is a syndrome, usually of a chronic or progressive nature, caused by a variety of brain illnesses that affect memory, thinking, behavior and ability to perform everyday activities. [4] Dementia not only affects the cognitive capabilities, especially memory and orientation, but also physical capabilities, which are associated with a decrease of physical activities.[5] Till date the research to find the cure for dementia is ongoing and no satisfactory and reliable cure has been discovered. There are therapies to influence symptomatic dementia beneficially and to improve the abilities remaining with elderly living with dementia.[6] These therapies provide a way to alleviate the quality of life and well-being of people with dementia.

This report aims at documenting the experiences of field study and developing of various therapeutic activities. An attempt was made to add elements of game design into the various activities developed, hoping to achieve more voluntary and enthusiastic participation and motivation of patients to perform various activities. This report holds rich insights for other designers who would be looking to build more inclusive activities to support elder people with cognitive disabilities.

2. Introduction

Dementia is an umbrella term for multiple progressive cognitive disorders. The word “dementia” can be broken down to “de”(without) and “mentia”(mind). Dementia is a serious medical condition which directly affects the brain and in turn every function of our body as brain is responsible for controlling everything. People in early stages of dementia usually start facing trouble in performing every-day tasks of life. Its initial signs are mild, like memory loss, confusion, mood changes, problems finding the right words, needing some help with planning or work. People living with dementia start having problems with walking, talking and swallowing food. In final stages they become fully dependent and may get pneumonia, infections, bedsores, multi-organ failure, and so on. [7]

India is under a unique condition where there is a rapid epidemiological transition which is leading to increased elderly population. Studies shows that Indian population also has higher susceptibility towards non-communicable diseases such as stroke and cardiovascular diseases which in turn may cause dementia. [3][8] As per the Dementia India Report (2010), an estimated population of 3.7 million people aged above 60 have dementia (2.1 million women and 1.5 million men). This is expected to double by 2035. [1][9]

To cater such a large population of people with dementia there are requirements for appropriate services and facilities. In India over the next few decades number of people with dementia will increase substantially and a large number of this population with dementia will stay at home longer. On the one hand this is due to the limited capacity of nursing homes and in-patient care facilities, on the other to the government policy to offer people in need of assistance/care

the opportunity to remain in their own homes as long as possible. As a result, the care for these elderly persons will have to be offered in the home situation much more frequently. [10] This will further lead to a rise in number of informal caregivers. Few other forms of services which prevail in India ranges from residential care facilities, day care centers, domiciliary care services, support groups, memory clinics and dementia help lines.[1]

Setting up these service centers does not suffice to tackle the incurable disease of dementia. Also the effectiveness of drugs therapies is quite limited hence non drug based therapies on dementia symptoms becomes essential. At the same time all these services are not always accessible to everybody in the current scenario hence there is a requirement for development of inexpensive therapies which can be carried by informal care givers in their own environment easily. Although many a times it gets difficult to convince patients to perform these activities as they might find them quite juvenile.

To learn more about the domain of dementia multiple field probes were made which involved informal and formal interviews with various stakeholders like neurologist, physician, care givers, dementia patients and their family members. A thorough study was done on care giving services of different types at Echoing Healthy Ageing (Domiciliary care), ARDSI – Dadar (day care) and Tapas, Pune (Residential care).

The insights from the field probes are documented in subsequent sections of this report.

3. Literature survey on therapies [6]

The main aim of multiple non drug therapies is to alleviate the abilities remaining to the patient. There are various therapies which have been well researched and practiced in domain of geriatric care for dementia. Music therapy, Art therapy, movement therapy and reminiscence therapy, memory training, reality orientation, validation therapy, self-maintenance therapy, behavior therapy, milieu therapy and staff training are to name a few. Due to existence of so many possible therapies, and on basis of suggestions of experts from the field probes music therapy, movement therapy and reminiscence therapy remained prime focus as far as the scope of this project is concerned.

Music therapy – As the name suggests music or musical elements are put to use for the purpose of healing. In context of dementia it mainly revolves around musical improvisation by the patient or simply listening to a piece of music. It helps patients to compensate for the ability to act and express themselves. Researches in the past have found music therapy to be effective in improving social skills, emotional state and diminishing behavioral problems.

Movement therapy [11] - This therapy can be used for a wide variety of patients at various stages of dementia and is mainly targeted to improve on the motor skills. This therapy helps on improving balance, stamina, strength and mobility. Proper amount of exercise or physical movements vitalizes and kindles the brain functions. The main goals of this therapy are

1. Revitalize bodily movements
2. Release psycho-physical tensions and sense of isolation

3. To stimulate constructive recall, reality contact and social interaction

4. To provide opportunities for expressing feelings

Reminiscence therapy – This therapy revolves around sharing of past experiences with others. It relies on triggering the nostalgia in patients. It puts patients in a situation where they start contemplating about their past experiences. The patient is taken through a deliberate jog through the major life events which can often be supported using photographs, films, audio or certain other tangible artefacts. The aims of reminiscence therapy are: to promote social interaction to the extent that new relationships may even be formed, to convey positive emotions (joy) and to promote the self-awareness of the dementia patient

Art therapy – This therapy aims at positively influencing the symptoms by either experiencing or creation of art in two or three dimensions. It is very effective in case where patients are speech impaired although can be demotivating for patients in case the task becomes too demanding.

For more details on other therapies you may have a look at the reference [6]

4. Field observations

Field study majorly was done in three parts at different places providing different kinds of services for dementia care. Field study was undertaken to understand the entire domain of dementia and its related care. Field study help me sensitize myself and also enable me to empathize and understand the various challenges which various stakeholders face who are involved in dementia care.

4.1 Echoing Healthy Ageing, Mumbai

Echoing Healthy Ageing is a social enterprise working towards improving the quality of life for people living with dementia by providing home based therapies. They provide education and consultation to families, caregivers and professionals working in geriatrics. A semi-structured interview was conducted with Ms. Amrita Patil Pimpale, the founder of EHA.

4.1.1 Key findings

Awareness about dementia is low

Post diagnosis support is weak

STM (Short term memory) and dementia are often mistaken

Art is most common form of activity conducted as it enables patients to express

Activities are supposed to be elder friendly (Maturity appropriate, and no cartoonish drawings)

Basic instruction based games are not preferred by patients who have good academic prior education

Activities should be relevant to keep patients engaged (could be related to their childhood)

Patients do enjoy doing activities involving physical movements

Patients are unable to initiate conversations but activities give a common topic to talk about

Progressive activities may work well with MCI (Mild cognitive impairments). Progressive activities here refers to the activities which has various stages of difficulty involved. Its equivalent to having various stages/ levels in digital games.

4.2 Tapas Elder care, Pune

Tapas is a Home care founded in 2016 by Ms. Prajakta Wadhavkar. At time of visit there were 34 residents in a four storied building with some spaces and basement converted to common meeting place. A lift is also there which can accommodate a resident with a wheelchair along with a caregiver.

4.2.1 Key observations

Caregiver to Resident ratio is 1 : 2

Residents were undertaking coloring activity of flowers

Few flowers were uncommon, in turn the colors filled went wrong and there was a slight lack of motivation

A list of celebration days was put up (Can an installation be created as an amusement for residents to be constantly reminded of events coming up and raise their excitement)

All of them liked listening to music

A rigid timing/ time table was followed for entire day

There were 19 females and 6 males with whom we got a chance to interact

4.3 ARDSI – Mumbai Chapter, Dadar

Alzheimer's and Related Disorders Society of India (ARDSI) is a registered national, non-profit voluntary organization engaged in the care, support, training and research of dementia.

At Mumbai they run a day care center, 6 days a week. At the time of visit there were six patients who used to visit this center regularly. They try and engage various patients into different activities for their well-being throughout the day. ARDSI has been instrumental in testing out various activities owing to its proximity and availability of patients throughout the week.

They do not have any fixed time table but depending on the mood of the patients they give them various activities to perform.



Fig 1. Tapas Elder Care, Pune

5. Identified areas of intervention

Designing activities for dementia patients

- Exploring if a game (here game refers to a play in which opponent's moves affects the other players) can be designed and if competitiveness has positive impact on performance
- Promoting physical movements while performing activities
- Exploring the measurable (performance) within activity and trying to record them. This records possibly can be mapped to stage of dementia and provide way to give a more personalized care

Game design to train the caregivers

Design ways to raise awareness on Dementia

6. Procedure for testing

Ethical approval was taken from the facility administrative. The gameplay was thoroughly explained first to the care givers and it was made sure the area of play was completely clear of any sorts of objects which might injure the players. Incase if the activities gets strenuous for any players, the caregivers and the player themselves reserved the rights to discontinue the play at any moment of playtesting. The players were then explained the rules of the game and play was carried under constant support of caregivers whom the players trust and feel confident with.

7. Play testing

Under this section the word 'player' and 'residents' have been used interchangeably, both are supposed to mean the same as person with dementia.

7.1 Orientation game

Spatial orientation is emerging as an early and reliable cognitive biomarker of Alzheimer's disease pathophysiology. [12] People with dementia often tend to lose their ability to navigate and also find it difficult to identify their spatial orientation. This activity even helps care givers an opportunity to even evaluate patient's executive functions. This game is based on exercising the executive functioning of brain and movement therapy. This game was play tested with 5 players at Tapas and 2 players at ARDSI.

Preparation required-

Orientation mat which can easily be printed out on a flex and is portable.

Sufficiently leveled and clear space to lay down the mat

Caregiver to assist player while walking



Fig 2. Resident in action while playing orientation game

Gameplay –

Players start from the demarcated starting point and they need to follow one colored line till its end.

There are bold arrows on each tile, landing upon any individual tile the player needs to reorient themselves in the direction of the arrow. Before traversing from one tile to another, they need to speak out loud/ show the card to indicate in what direction are they going to traverse to follow the demarcated line.(Forward, Backwards, Right, Left)

Two players are supposed to play against each other as a race to the finish.

Basic game loop

Speak out direction > Traverse > Reorient > Speak out direction

Results and insights from orientation game

The game involved too many decisions to be taken in one move and the players tend to forget what was supposed to be done after each step. This implied that game for people with dementia should not involve too many rules/ task in a single move.

Players only stuck to the moving along the line which seemed easy for them to follow. Inference can be drawn that initial few moves for game should be very easy so as to make the player comfortable and not bombed with a difficult situation right at the beginning of the gameplay.

Reorienting led to confusion while game play, players sometimes started following the line towards the start position itself.

When reorientation arrow was in opposite direction of the flow of demarcated line to follow, players easily committed mistakes as they lost all visual cues.

The mat being huge and physical in nature attracted the attention of many residents and they willingly were asking us if they could participate. This implies that visual appeal of the tangibles should be very high so as to motivate players.

Good thing about this game was that even spectators participated by shouting out loud some hints when player got confused.

All spectators as well as care givers motivated the player by clapping and cheering which even led to repetitive play by few players.

Initial idea was to hand out the cards of directions to players, though it did not work out well as usually the player required assistance while moving around. So we can infer that games involving physical traversing should enable players to keep their hands free so as to move around freely.

Eventually the reorienting was dropped while play and player moves was restricted to speaking out the direction they are to traverse next and moving to the next tile.

7.2 Song completion blocks

This game is designed on the foundations of music and reminiscence therapy. Wizard of Oz technique was used to test out this game.

Objective and gameplay

A song's audio clip is broken down into 4 chunks and each block with distinct pattern on it represents one out of the 4 chunks of that song. Player has to rearrange the blocks so as to crack the correct sequence of the entire 4 chunks of the song. There is a designated play the block zone where the player can place individual block and get to hear the chunk of song associated with it. After hearing all the blocks individually the player has to rearrange the four blocks in the correct sequence of the song.

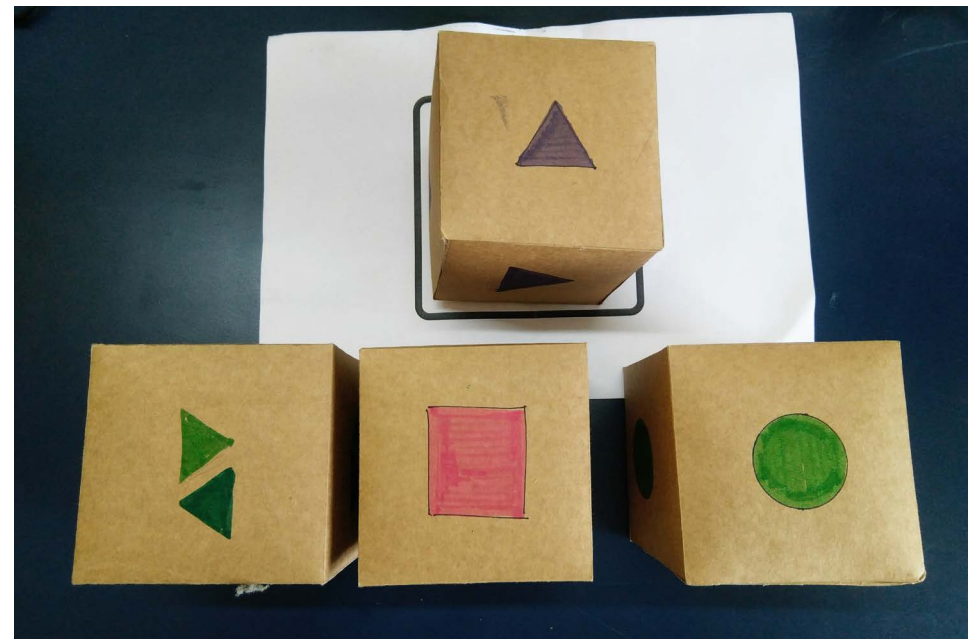


Fig 3. Block placed in play-o-block zone

Results and insights from song completion blocks

The length of the chunk was usually too long (30-45 secs) which led to issue with retention.

Players could only guess the correct sequence of only first block if they luckily happened to play the initial part of the song. This implies that people usually can only remember the beginning of the song and usually not the entire song.

Players did start humming the song although the game was difficult for them to accomplish.

Due to lack of visual cues it was cognitively very taxing for players to associate pattern to the chunk of music. A possible alternative could be also playing the chunk alongside the original video from the movie.



Fig 4. Shows the cards laid out on the table for card matching game

7.3 Card matching

This game was intended for players to reminisce about their past by answering the probing situational questions. The cards are designed in such a way that one face has a question and the flip side has a graphic on it. The questions were basically from these major themes – Related to family, favorite things, Generic orientation questions related to date and time or some past milestones from school or work life. The graphics were pairs of everyday objects which players usually see around them. This was aimed to generate social confidence amongst the player and possibly a good conversation starter by going down the memory lane. The objects were useful in their activities of their daily life. (ADL)

Gameplay of card matching –

All cards are laid on the table with multiple players sitting around it. One player starts to pick a card at random, answers the question on it and subsequently flips it over to display the graphic on it. The graphics on the card exists in pair of two (eg. Brush on one card and there will Toothpaste on some other). Whenever any player forms a pair, the player can claim those two cards. The player with maximum collected pairs wins the game.

Results and insights from card matching

Few players in early stages of dementia sort to look out for relations between the question and the graphic at back. This could be a possible way of designing a new game with which the graphic at the back could be a way to further lead the discussion regarding the question on the front.

The reward of collecting cards was not motivating enough, many players put back their collected cards and mixed with other cards on the table.

Once the card is flipped to the graphic side, players had a tendency of re-picking the card having graphic instead of the one with question on the top. Probably the cards graphic design is required to be altered in a way the question side is equally catchy!

Instructions must be given in the most familiar language.

Motivation of players to play increases if the care givers also get involved in the play.



Fig 5. Players narrating their stories during card matching gameplay

8. Conclusion

This project gave me an overview as well as a quite in depth understanding of the vast domain of dementia and related services. Most of the activities designed were unable to meet the desired goals of play, however these was tremendous learnings from first prototypes which will lead to much richer iterations.

The rich insights in this documentation will surely serve as a great starting point for anyone who wishes to design interventions in domain of dementia.

Coming to the activities, their success can only be judged by a longitudinal study and repeated sessions of gameplay with the people with dementia.

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