Service Design for Assisted Home Care for Dementia Patients

Project 2

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Abbreviations

- PlwD(s) = Person(s) living with dementia (Dementia language guidelines; 2018)
- 2. AHC = Assisted Home Care
- 3. CSI = Caregiver's Stress Index
- 4. ADL= Activities of daily living
- 5. MSW= Master in Social Work
- 6. QoL= Quality of Life

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1. Introduction

1.1 About Dementia:

'Dementia is a term used to describe a group of brain disorders that will usually impact memory and orientation to time, place and person, the ability to think and communicate. Mood and behavior can be affected alongside a decline in the skills and abilities of everyday life. The cognitive impairment is such that someone with dementia cannot learn new information.

Dementia persists over time and is irreversible.' (Walsh; 2006)

According to the Alzheimer's Association, 50 million people are living with Alzheimer's and other forms of dementia worldwide. Symptoms of dementia consist of a decline in memory, a decline in cognitive functions, and a decline in awareness of the environment. (Waite et al.; 2009)

Decline in memory can be characterized by difficulty in taking in, difficulty in retaining and recalling matters in its mild forms. As the decline progresses to a moderate level, the person may start having difficulty in recalling basic information about local geography or even the names of familiar people. As it

progresses further into a severe stage, there is a complete inability to learn new information and they may as well be unable to recognize close relatives. (Waite et al.; 2009)

There might also be a decline in other cognitive functions like judgment and thinking, planning and reasoning, processing of information which also ranges from mild to severe where inability to undertake complicated tasks falls under mild while absolute absence of ideas falls under severe decline. (Waite et al.; 2009)

The decline in awareness of the environment is characterized by absence or clouding of consciousness and a decline in emotional control and motivation emotional lability, irritability, apathy, coarsening of social behavior. (Waite et al.; 2009)

Doctors might usually wait for 6 months and consistents symptoms for a confident diagnosis

1.2 About Tapas Elder Care:

Tapas Elder Care, Pune is located in Pashan, Pune in the state of Maharashtra, India. Tapas was founded by Mrs. Prajakta Wadhavkar with a vision of providing compassionate, person-centric treatment and care to persons with dementia. Tapas has a well-informed and specialized board of advisors which consists of experts from the domain of geriatric care, psychological and psychiatric health, palliative care, etc. Tapas has its own panel of doctors and in-house nurses to take care of the physical and mental well-being of not just the PlwDs but also their families.

The culture observed at Tapas is extremely joyful and informal yet they display high professionalism and diligence. They have a 'no compromise in care' approach towards work. The approach of Tapas is to provide an environment of love and care and help them lead a life of dignity. This is achieved through a well-structured schedule, customized routines, and creative activities.

At Tapas, the objective is to keep the PlwDs engaged active. Keeping them engaged in activities of their choice reduces their chances of becoming agitated or aggressive rather than administering a sedative.

The caregivers, called counselors are postgraduates in Masters in Social Work (MSW). They are highly compassionate, gentle and empathetic towards the PlwDs. They are keen to understand the person and create personal bonds with them. Many of them pick up the regional languages of the PlwDs in order to communicate with them better.

With the implementation of the new services for domiciliary care as well, Tapas intends to carry these values forward and translate them into care at the respective homes of the PlwDs.

2. Literature Review

Dementia care is a complex service and the demand for healthcare services is increasing due to higher life expectancy. aging population, and lifestyle changes. (Bloom et al; 2010). In healthcare, there are multiple stakeholders, like the patients, their families, caregivers, doctors, nurses, facilities. housekeeping, pharmaceutical industry, government, etc. The vision of this project is to involve multiple stakeholders to improve the quality of life (QoL) of the families of PlwD. 'The value of services is co-created through a customer's experience through varied, contextualized, service encounters in which interactions with several touchpoints constituting a coherent ecosystem take place. Service design calls for multidisciplinary participation that poses challenges due to the diverse backgrounds, skill sets, and experience of the collaborators.' (Khambete et al.: 2015). In this project, we closely work with Tapas Elder Care, Pune Tapas believes in understanding their customers well and connecting them on a personal level. Thus their employees are highly empathetic towards the PwDs and their families.

Service employees are an important factor in service design as they form emotional and personal connections with the customers (De Ruyter and Wetzels: 2000) Planned and well-detailed interventions and interactions are required at every stage of the customer journey to lead to desirable outcomes. 'Integrating design in health with multi-stakeholder groups requires good planning. Deciding on the degree of community participation where time and costs are limited is necessary' (Lauren Tan, Deborah Szebeko; 2009) In this project, the professional caregivers (in this case caregivers from Tapas) play an active role in the care of PlwD at their home itself. The framework proposed in this project is an iterative process of assigning appropriate and assessing the assigned resources to optimize the care routine. A co-design approach, the professional caregivers and the family are entailed to reflect on their experiences of service and working together towards identifying improvements, devising and implementing changes and then reflecting on what works and what does not in an iterative way (Sara Donetto et al.; 2014)

Dementia affects the memory of a person and they may feel disoriented. It also affects their cognitive abilities along with mood, behavior, and personality. (Walsh; 2006)

Every family member will have a unique bond with the person living with dementia. So there is no one pattern of involvement in care routine that will or should suit everybody. (Woods et al; 2007). Thus the services need to be flexible and customizable according to the dynamics of the family in focus.

In this project, the main goal is to improve the Quality of Life (QoL) of the family members caring for a person living with dementia. The mental well-being, caregivers' stress and quality of life of the family of PlwD can be assessed using multiple scales and multiple parameters available like

- time available to address their own needs(Rashmi Gupta; 2007)
- Positive mental attributes like resilience, spirituality, self-esteem, self-efficacy, etc. (Nicola A. Cunningham et al.; 2018)

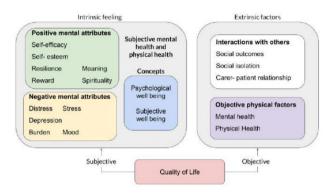


Image source: Understanding and Measuring the Wellbeing of Carers of People With Dementia (Nicola A. Cunningham et al.; 2018)

The process followed for ideation in this project was using pattern language for service design. Pattern language provides a framework that has emerged through practical experiences and which works well in the healthcare domain. It is not very prescriptive yet recommends interventions in a structured manner (Khambete; 2011)

The evaluation of the project will be done by expert evaluation through the Delphi Techniques. Two rounds of the Delphi technique will be conducted (Hsu and Sandford; 2007). The first round will consist of experts reviewing the project and answering a questionnaire followed by the second round where there will be a discussion amongst the experts based on their responses in the first round.

For forming the questionnaire, the VIPS framework for person-centered care for PlwDs in nursing homes (Brooker; 2004) can be used.

3. Secondary Research

3.1 Cognicare









3.1.1 Advantages

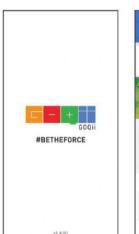
This application provides good articles and tips for reading. It covers extensively most of the problems faced in dementia. It gives information about different therapies and activities that can be conducted.

3.1.2 Drawbacks

More active participation would be required from service providers to tackles difficult situations.

In day to day chores as well, only reading might not help. Some amount of training might be required.

3.2 GoQii







3.2.1 Advantages

This application provides more active participation from experts like video sessions and coaching.

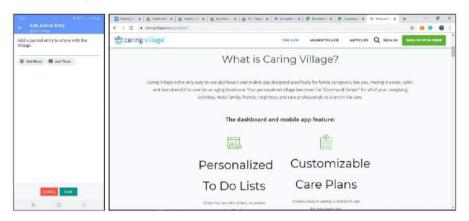
It shows progress in activities, health trends and is a collaborative platform, meaning, it can be viewed and monitored by multiple family members.

3.2.2 Drawbacks

This is, however, a generic healthcare and lifestyle app.

This does not provide specific training or services for dementia which is extremely necessary.

3.3 Caring Village



3.3.1 Advantages

This application is a collaborative platform for family members to care for a PlwD.

Multiple stakeholders and family members can be a part of this and can volunteer to help in the care routine.

It also helps organize and monitor the routine in a better manner

3.3.2 Drawbacks

This application does not bring in the human values that human caregivers would bring. Human support caregivers can bond with the customers and provide emotional support as well.

An application like this as a supporting service with human touchpoints can be incorporated for better organization and monitoring as well as personal and emotional bonding

4. Primary Research

Primary research for this project consisted of

1. Interviews with families:

- a. Semi-structured interviews with branching and laddering with 9 families having persons living with dementia.
- b. The interviews were conducted after obtaining informed consent from the families.
- A lot of insights were triangulated by collecting data from family, professional caregivers and doctors and other experts at Tapas
- d. Insights:
 - Families cannot identify the need for specialized care for dementia.
 - There is very little awareness about dementia and how to manage the symptoms.

- iii. The nurses from general bureaus are only capable of maintaining basic hygiene of the PlwD; they are not trained to manage conditions of dementia at home.
- iv. Family members get frustrated or helpless and do not always realize that the behavior of the PlwD is caused because of the condition.



Image source: Author

2. Interviews with professional caregivers and doctor:

 a. Unstructured interviews with 5 counselors at Tapas

b. Insights

- It is necessary to understand the background of the PlwD in order to make a better connection and help them better
- ii. It takes some time, effort and a lot of patience to understand what works and what does not with a particular PlwD
- c. Dr. Aditya Patil, Chief Psychiatrist at Tapas Care
 - Knowing the background of PlwD helps in positioning the treatment on the spectrum.
 - ii. The symptoms are just the top layer; the causes of the symptoms might be rooted

deep. Doctors need to patiently find the cause of the trouble

3. Interviews with the founder of Tapas Elder Care, Mrs. Prajakta Wadhavkar:

- a. If a family is looking after a PlwD for a long time, the primary caregiver develops tremendous stress and may show symptoms of mental disorders like depression.
- Family members interpret the symptoms of dementia very differently and the interpretation varies from person to person. Therefore, for proper diagnosis, medical reports are required.
 Eg. MRI Scan

4. Shadowing professional caregivers during their daily work routine:

a. Tremendous amount of empathy and patience is required

Assisted Home Care for Dementia Patients



Image source: Author



Image source: Author

- 5. Session for caregivers by renowned psychiatrist, Dr. Anand Nadkarni on 'managing stress and grief in care routine':
 - a. Caregivers need support and help to manage their stress and frustrations
 - b. Caregivers also need support in times of grief
 - c. Caregivers need to be aware of their emotions

5. Goal of the Project

- Help PlwD and their families lead a life with better quality
- 2. Help families manage conditions of dementia in PlwD at their home
- Co-creating value with and for the families of PlwDs by multiple stakeholders

PlwD:

- 1. Better Quality of Life<ref>
 - a. Medically as fit as possible
 - b. Balanced diet
 - c. Enough physical activity
 - d. Enough mental activity
 - e. Maintaining social life

Family of PlwD:

- Better Quality of Life (Rashmi Gupta; 2007, Nicola A. Cunningham et al.; 2018)
 - a. Time to meet their own needs

- b. Spend quality time with other family members
- c. Physical exercises
- d. Mental exercises
- e. Time off from caregiving duties
- f. Plan for the future: Financial/ in terms of caregiving routine
- g. Have a social life
- h. Ready for facing emergency situations
- Know what to expect in the future in terms of the progress of Dementia
- 2. Organizing their life around Care routine
 - a. Have volunteers help from time to time
 - b. Have experts analyze and provide the best possible solutions
 - c. Have help in managing the care routine

6. Ecosystem Map

Through primary research, multiple stakeholders in the dementia care domain were identified. Iterations of the ecosystem map were made to refine it.

The PlwD, their family and Tapas Elder Care form the core of the services. (shown with bold connections)

Tapas and the family of the PlwDs are the primary value co-creators while the family and the respective PlwD would be the primary beneficiaries of the service.

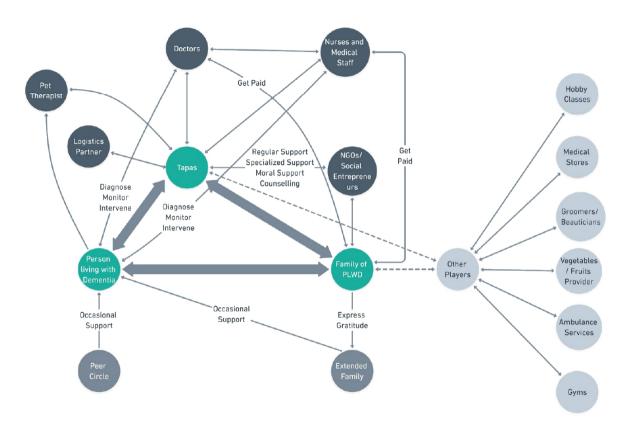
The primary customers in this service are the family members and the service provider is Tapas ElderCare.

Tapas has a panel of experts and doctors that can be leveraged in this service. Tapas also has trained nurses specializing in dementia care on their premises. They could play an important role in care at home.

Other players consist of miscellaneous connections which would prove to be beneficial to the family.

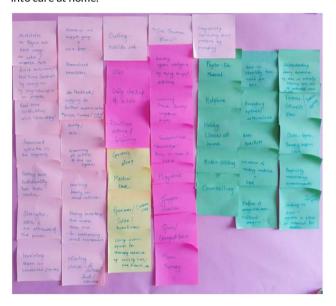
Some flows between the entities of the map have also been identified. At every stage of designing interactions, these flows have been taken into consideration and a suitable touchpoint is designed.

In the pilot implementation of this service, Tapas Elder Care, the doctors, nurses and the panel of experts is in focus with other players playing peripheral roles.



7. Ideation

Pattern language for service design was used in the ideation process. A framework of the existing practices at Tapas was available. Brainstorming was done to innovatively translate into care at home.



Ideas

- 1. Hobby classes at home
- 2. Elder sitting
- 3. Counseling
- 4. Helpline
- 5. Psychoeducation material
- 6. Sticking to the time a system in place for overtime payments
- 7. Explicitly mentioning the commitments expected from the family members
- 8. Clubs, Gyms and therapy session visits to different places for the PwD
- 9. Victoria Stilwell/ Jackson Galaxy's show model giving tools and training and follow up in coming weeks

- 10. Tools to understand family dynamics- who is actively participating to help, who can be motivated to help more
- 11. Putting up profiles of caregivers on display- "official experienced caregivers"
- 12. Blogs by the board of directors/ experts
- 13. Collation of reading material and FAQs
- 14. Best practices
- 15. Providing options/alternatives in activities/caregiving plans according to requirements or budgets
- 16. Tools to identify the need for AHC
- 17. Setting up a routine and following it
- 18. Daily checkup of vitals
- 19. Creating a diet plan and following it
- 20. Music therapy

- 21. Quiz/completions
- 22. गप्पा/ chatting (Gupp-Shupp)session
- 23. Playtime
- 24. Touchpoint has knowledge. Show it. Make it visible to the family
- 25. Involving friends, extended family, neighbors, society friends in some sessions or activities
- 26. Building system intelligence by trying out things/activities- this combination of activities x,y and z worked for person with l,m,n symptoms. Person b has similar symptoms. The same activities might work.
- 27. Grocery store tie-up
- 28. Medical store
- 29. Groomer/Beautician/Salon-Urban Clap

- 30. Using public spaces for therapy sessions- society hall, park benches
- 31. Progressively narrowing down problems by branching
- 32. "The Truman Show"
- 33. Outing-outside work
- 34. Offering choices- of clothes/food/activities
- 35. Involving them in household chores
- 36. Putting back individuality into their routine- strengths, skills and positive attributes of the person
- 37. Finding something that makes them tick- for customizing care and engagement
- 38. Activities to figure out the best ways to calm or engage a PlwD
- 39. Quick assessment or real-time feedback by caregiverseg. Physiotherapist on progress

- 40. Real-time notifications while "elder sitting"
- 41. Supervised activities in the beginning
- 42. Involving family in some activities
- 43. Knowing all entities of the ecosystem
- 44. Buddy or Host
- 45. Admission into support group
- 46. Online forum
- 47. Feedback or logging for further customization-"worked" or "did not work"
- 48. Personalized newsletter

8. Categorizing into concepts

The ideas were then categorized into broader concepts based on the affinity of the ideas by combining and mixing multiple ideas. The concepts were then divided into three categories based on the functional beneficiary of the concept.

8.1 Concepts that help the family:

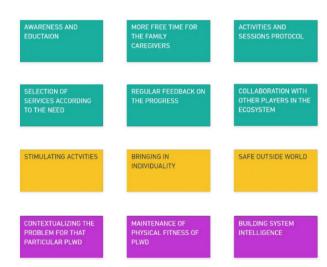
- 1. Awareness and Education
- 2. Selection of the services according to the need
- 3. Activities and sessions protocols
- 4. Regular feedback on the progress
- 5. Collaboration with other players in the ecosystem
- 6. More free time for family caregivers

8.2 Concepts that help the PlwD:

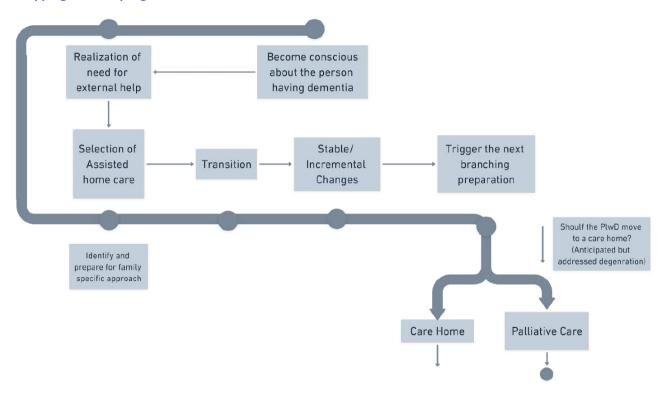
- 1. Safe world
- 2. Stimulating activities
- 3. Bringing in Individuality

8.3 Concepts that help the Tapas caregivers

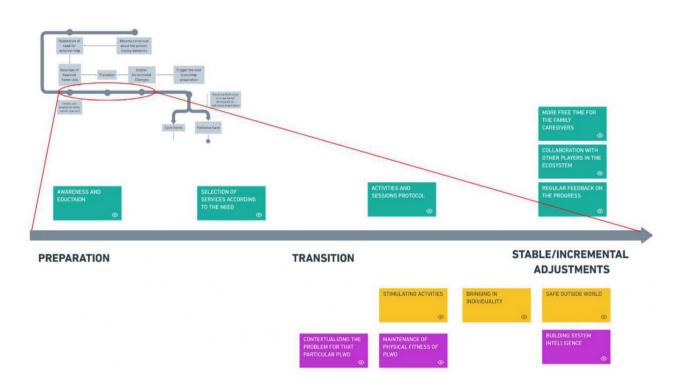
- 1. Contextualizing the problems for the particular PlwD
- 2. Maintenance of Physical fitness of PlwD
- 3. System Intelligence



9. Mapping the user progression



10. Mapping of Ideas on the Progression



11. Final Concept - E. A. S. E.

The final concept developed consisted of a four-stage service framework.

This service consists of experts assessing the situation using different assessment techniques and addressing the problems using customized solutions for and with the family.

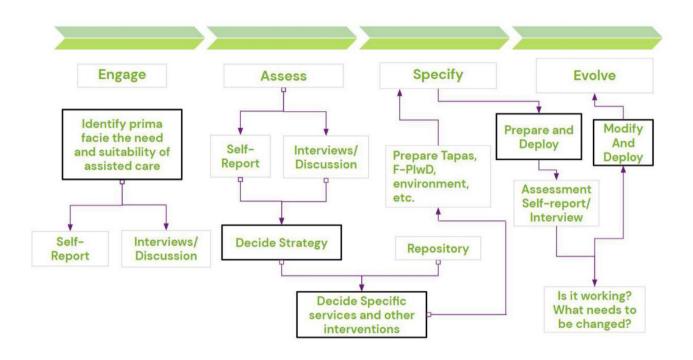
Phase 1

- E: Engage:- 'Engaging' involves identification of the need for assisted home care (AHC) and engaging with Tapas Elder Care for the same
- A: Assess:- 'Assessing' involves assessing what might
 work best for a particular family. Assessment includes
 family interpretations of the problem, observations by
 Tapas experts at the home of PlwD and medical
 diagnosis like MRI scan, neuro-psychoanalysis tests, etc.

Phase 2

• S: Specify:- 'Specifying' involves assigning specific

- resources and tools that might suit the family in the most optimized way.
- E: Evolve:- 'Evolving' involves aligning and adjusting what works and what does not work in the newly implemented service. It is basically fine-tuning the services to best suit the PlwD and the family. This will be done by logging the progress and performance regularly and sharing it with experts for analysis. The requirements of the family may also evolve with time as the dementia progresses and the symptoms change.

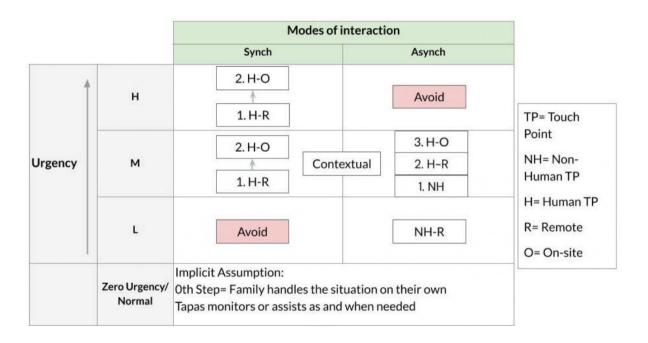


12. Customer Journey Map

The following customer journey map depicts what the family is thinking, feeling and doing during the different stages of the service.

Stage	Engage	Assess	Specify	Evolve
Stage Goal	Identify the need for AHC Initial call for help	Identifying the exact problem	Assigning optimum and appropriate resources	Adjusting to the new interventions
Stage Context	The need for AHC is established	Narrowing down the problem and services	Matching compatibility and optimizing	Iterations and improvements
Thoughts	I wish to provide the best possible care. / I cannot handle these situations.	what is best for my loved one? what will solve these problems?	will this work best for my loved one? I hope this solves the problems	this is working. what next? how will this continue? will it continue to be smooth?
Feelings (using Plutchik's wheel of emotions)	apprehension, anticipation, pensiveness	apprehension, anticipation, pensiveness, serenity	apprehension, anticipation, pensiveness, serenity	apprehension, anticipation, pensiveness, serenity
Normal Activities	Daily house chores, work	Daily house chores, work	Daily house chores, work	Daily house chores, work
Journey Related Activities	Booking an appointment, articulating the problems	Meeting with experts, letting experts /support staff observe activities at home	understanding the activities and interventions	participating in activities, noting things that work, reporting

13. Strategy for Designing Interventions



The strategy shown is used while designing interactions between the service provider and customers.

The implicit assumption in any situation is that the family will try and handle it on their own.

The level of urgency will be determined depending on the timeframe available to act and the immediate physical harm possible to the PlwD as well as the caregiver.

Synchronous interactions are to be avoided for low urgency situations and the human resources are to be spared wherever possible. Conversely, asynchronous interactions are to be avoided for high urgency situations which might be usually stressful. The mid-level urgency situations need to be assessed based on the context which will require some expert analysis. The mid-level urgency situation will eventually move to low urgency or high urgency level and the tendency of a particular situation to move up or down the urgency axis will determine the kind of intervention.

Generally, the interventions will begin in asynchronous mode moving to synchronous mode; non-human touchpoint to human touchpoint and remote to on-site interventions.

Overall themes for the interactions are as follows:

Professionalism: Tapas has a 'no compromise in care' approach towards work. A similar attitude and approach should be visible in any interventions designed

Flexibility: This being a dementia care service, it needs to be flexible to accommodate the changing conditions of dementia in a person. The symptoms are different from individual to individual and also different in the same person at two different times.

Using available means of ICT: Tapas is an organization that has grown very organically. Therefore, publicly and easily available means for ICT like WhatsApp, Gmail, Google docs, etc. are used in this project.

With the implementation of the new services for domiciliary care as well, Tapas intends to carry the values of empathy, compassion, and professionalism forward and translate them into care at the respective homes of the PlwDs.

14. Personas

14.1 Joshi Family

The Joshi family lives in Baner, Pune.

It consists of: Mr. Madhav Joshi, a 74-year-old man, retired as a senior officer from a nationalized bank. In this story, we shall refer to him as Joshi Aajoba (आजोबा/ Aajoba = Marathi term for Grandfather).



His son, Mr. Shailesh Joshi is 45 years old and works in an MNC. Mrs. Aparna Joshi, his daughter-in-law, is 42 years old and is a housewife. Shailesh and Aparna have a daughter, Neeraja, who is 17 years old studying in junior college.



Aparna Joshi

Neeraja Joshi

Mrs. Malti Joshi, Shailesh's mother, passed away 3 years ago due to a heart attack. Since then Joshi Aajoba has been a little low.

The Joshi family used to stay in Kothrud for a long time. But as Neeraja grew up, the 2 bedroom apartment started falling short of their requirements and they moved to a new and bigger house with 3 bedrooms in Baner. Joshi Aajoba was not very happy to move to a new locality. He had a group of friends in Kothrud. There are a few people of his age in the new residential complex in Baner, but he is not very keen on meeting new people. Shailesh was not very happy either to

make his father move to a new place. But it was a practical decision that he took, or so he thought.

It has been 2 years now since they moved to the new home. Shailesh's workplace is a little nearer to the new home than the older one. Aparna has met new friends and has joined her society's club. Neeraja is also busy with her college work and studies.

The usual day of the family begins with Aparna getting up at 6 am and waking Shailesh up. They have their morning tea together and proceed towards their daily chores. Joshi Aajoba is usually up by 6.30-7 am and prefers to have his morning cup of tea. Shailesh gets ready to go to work and Aparna prepares breakfast and packs his lunch. By 7 am Neeraja also gets up and starts getting ready for college. By 8, Aparna sees Shailesh off and he leaves for his office in his car. His office timings are from 9 am to 6 pm. But due to the heavy traffic in Pune. Neeraja also leaves by 8 for her classes.

Aparna and Joshi Aajoba then have breakfast and Joshi Aajoba proceeds towards his prayers. He then reads newspapers and calls up a few friends from his older society. Aparna retreats to

her room for some alone time. She reads and listens to music. She loves singing and playing the harmonium. But hasn't had any chance of getting formal training yet. By 12.30, Aparna starts making preparations for lunch. Neeraja comes back home by 1 and Neeraia, Aparna and Joshi Aaioba have lunch together. After lunch, Joshi Aajoba goes to his room for a nap and Neeraja to her room for completing her assignments and homework. Aparna watches TV for a while. By 2.30 pm, their domestic help. Geeta Maushi comes for cleaning the house and washing utensils. She works till 4 pm. Meanwhile, Aparna takes a powernap and completes her daily work for the society's club. Aparna is a graduate of commerce, so the accounting work of the club is her responsibility. The club is of a small scale and through the club, the ladies of the residential complex arrange workshops for local kids and volunteer for social causes around their locality. By 4.30 pm Aparna and Joshi Aajoba have their afternoon chai and snacks. Neeraja joins them for snacks. She leaves for her badminton classes and tuitions at 5. Aparna then goes to the club and meets her friends.

Joshi Aajoba watches TV for a while. Aparna returns by 6.30 pm and brings vegetables and fruits along for preparing dinner. Joshi Aajoba continues watching TV till 7. At 7 pm, Joshi Aajoba sits by the window and watches down on the road. By 7.30 pm, Shailesh returns from his work and relaxes in his living room. They all watch a music reality TV show together. Neeraja returns by 8.30 pm. Everyone is usually waiting for her to begin dinner. They have dinner and sit together in the living room till 10 pm. After 10 pm, Neeraja goes to her room to continue her studies and homework. Shailesh retreats to his room and logs his daily expenses in his diary. He also asks Aparna for her expenses. Aparna fills up water bottles to be kept in Joshi Aajoba's room and their room and retires to the room for the night. Joshi Aajoba goes to his room and plays the radio for a while. He then goes off to sleep by 11 after switching the radio off.

Just a few kilometers away, there lives another family.

14.2 Sharma Family

Mrs. Narmada Sharma is 70 years old. Her husband Mr. Mahadev Sharma is 75 years old.

The Sharma couple has two sons who live in the US.



Mrs. Narmada Sharma

Mr. Mahadev Sharma

Narmada and Mahadev Sharma used to work in the post office and retired 10 and 15 years ago respectively with a government pension. The Sharma couple stay in their 2BHK home in Pune.

They used to go for evening walks and clubs. But three years ago Mrs. Sharma was diagnosed with dementia. Mr. Sharma had

been looking after his wife for the past 3 years but her dementia was progressing and her health was deteriorating. Their usual day begins at 7 am when Mr. Sharma gets up and gets ready. Mrs. Sharma gets up around 7.30 am but sits in her armchair for a while.

Their maid Meena Mavshi comes at around 8 am. Meena Mavshi prepares tea for the Sharma couple, cleans the house, washes utensils, prepares breakfast and lunch for them, and helps Mrs. Sharma with her clothes before she goes for having bath.

Mrs. Sharma has trouble walking around in the house and needs help to go to the washroom and do other chores.

Mr. Sharma himself is quite old and tired now. Mr. Sharma had been trying to give the best care to his wife but because of his own age that was becoming difficult day by day.

By 9 am the Sharma couple has breakfast and Mr. Sharma gives Mrs. Sharma her medicines. After breakfast, Mr. Sharma helps Mrs. Sharma to the room and she sits in the balcony humming. Mr. Sharma reads the newspaper and then puts the used clothes in the washing machine for washing.

By 1 pm, they have lunch and then proceed to take a nap till 4 pm. After getting up Mr. Sharma prepares tea and then both of them have tea.

Mrs. Sharma then watches TV. Mr. Sharma goes to the park nearby to meet his friends and they sit o the park bench chatting.

By 6 pm he comes back while Mrs. Sharma continues to watch TV. Meena Mavshi comes again at around 6.30 pm and prepares dinner. Meanwhile, Mr. Sharma watches TV with Mrs. Sharma. By 8 pm they proceed to have dinner. Mr. Sharma cleans up after their dinner and by 9.30 pm they go to bed.

15. Scenarios

15.1 Joshi Family

Once, Joshi Aajoba was having his lunch with his Aparna and Neeraja like usual. While eating chapati, Aparna saw that Joshi Aajoba seemed a little confused. He had a piece of chapati in his hand but just kept staring at his plate. "What happened, why are you not eating?" she asked. "Huh?", Joshi Aajoba hurriedly put the piece of chapati in his mouth and gulped it down with water. Aparna found it weird but did not question further. That night over dinner, Aparna kept a close eye on Joshi Aajoba to see if he was eating fine. He was quite okay other than the usual "No. I am full" tantrums.

A few days went by and one day, Neeraja came running to her father panicked and said, "Aajoba won't come out of the bathroom. He is standing there staring at the overflowing bucket." Shailesh hurriedly went into the bathroom and asked Joshi Aajoba what was wrong. But he would not reply. Joshi Aajoba was drenched as he had first started the overhead shower. Shailesh held his father's hand and tried to lead him out of the bathroom upon which Joshi Aajoba jerked off his hand.

Shailesh had a tough time getting his father out of the bathroom. But after a while, he was quite fine and behaved as if nothing had happened. Shailesh and Aparna got worried and tried to talk to him about it. He just smiled away and did not answer anything.

Such incidents of forgetting and confusion continued for a while and the family was getting increasingly worried.

Sometimes, he would keep asking when Shailesh would return from his work. Other times, he would wear his clothes inside out. The family kept seeing some changes over time but wasn't sure what exactly was happening. However, Aparna was getting worried and she would avoid leaving Joshi Aajoba alone in the house. She was not going out to meet her friends from the club and she would order the vegetables from the regular vendor. He would deliver the groceries and vegetables at home. On another such night, Shailesh got up to use the washroom when he heard some noises from the kitchen. He went to the kitchen to see Joshi Aajoba trying to make tea. "What happened, Baba? Do you need something?"

"I am making my morning cup of tea. Do you want it too?" replied Joshi Aajoba. "It is 2 am in the night. Why are you making tea right now?", Shailesh was shocked. But just waited with his father till he made tea. That night, Joshi Aajoba kept pacing across the house. Shailesh could hear him walk outside his room but he was not sure what to do. He had tried asking his father to go to bed but he would not pay heed. He would peep into Shailesh's bedroom once in a while, walk up to his side of the bed and go out of the room if asked what was wrong. He kept doing that all night.

The next morning Shailesh discussed the incident with Aparna and both were convinced that they should consult their family doctor. They decided to go on their own first.

After telling the doctor the whole story, the doctor suggested consulting a psychiatrist. He suggested a psychiatrist he had known. Aparna booked an appointment and they went to meet the psychiatrist a few days later.

The psychiatrist told them that there was nothing to worry about as such things keep happening due to old age. He said that due to old age, the sleep hours get reduced, sometimes

older people get confused about what to eat and how to eat, etc. He, however, suggested to get an MRI scan done so that they would know the exact reason and would be able to address it well. The doctor suggested that it might be the onset of dementia or it could be depression.

Shailesh and Aparna convinced Joshi Aajoba to let them take him to get an MRI scan done. The results came in and the doctor told them that Joshi Aajoba had dementia.

He assured him that it was absolutely manageable and that they need not worry. That night, Shailesh decided to read about dementia online. While going through various resources online, he came across the Tapas ElderCare website. He saw that it was a facility close to their place and showed it to Aparna. They decided to check it out.

15.2 Sharma Family

Mr. Sharma used to go and meet his friends in their building but since Mrs. Sharma's health is deteriorating, he cannot do so nowadays. He is also confined to the house with her.

Sometimes she becomes aggressive and refuses to eat. She has trouble sleeping as well. She keeps awake at night, in turn, disturbing Mr. Sharma's sleep as well and keeps dozing off throughout the day. Napping while watching TV has become a regular for her now. Every time Mr. Sharma tries to wake her up, she becomes agitated.

Both of their sons are also worried but can do little from where they live. They visit their parents at least once a year with their families. That is the happiest time for Mr. and Mrs. Sharma for they get to meet their children and grandchildren.

This time during their visit, they decided to find some assistance for their father to take care of their mother. They hired a nursing assistant but she wasn't trained to deal with dementia conditions and the situation ended up becoming worse. The assistant would lose her calm and Mrs. Sharma would yell at her. The assistant would yell back. It was more

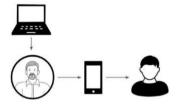
distressing than ever for Mr. Sharma.

The sons then found about Tapas Elder Care on the internet and suggested that to their father. Mr. Sharma was extremely unhappy with placing Mrs. Sharma in a care home which is when their sons explained to him about assisted home care. Mr. Sharma decided to look int it and asked for the contact number of Tapas Elder Care.

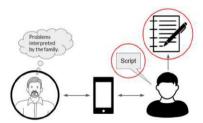
16. Service Encounter Blueprint

The service blueprint is illustrated considering the Joshi family. However, it will be similar for the Sharma family as well with some contextual tweaking. The following illustrations depict an overview of the service encounters.

1. Shailesh calls on the number provided on the website



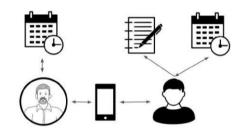
Shailesh explains his problem in brief.
 Tapas staff explains about Tapas and invites to visit



3. Booking an Appointment



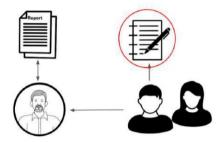
4. Date and time is fixed eventually



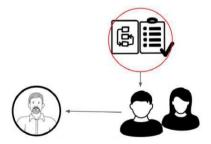
5. Confirmation



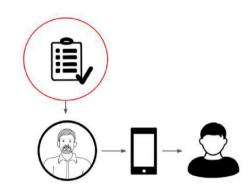
- 6. Shailesh visits Tapas
- 7. Shailesh details out the problems that the family is facing



8. Plan of Assessing is discussed



9. QoL Assessment



10. Medical Diagnosis

MRI scans, Neuropsycho analysis, etc.

11. Expert Observation



12. Analysis of data collected



13. Discussion with family, explaining goals and training



- 14. Carrying out activities
- 15. Monitoring
- 16. Improving

The detailed version of the service blueprint is attached in the coming pages.

16.1 Engage

STEP	Initial call for Enquiry	Booking Appointment	Arrive for Visit	Meeting	
STEP GOAL	Understand the service	Schedule a meeting	Initiate meeting	Understand which service suits best	
USER ACTION	Call Explain the situation	Reply to the message Recieve confirmation	Arrive at Tapas Tour of Tapas	Discuss primary symptoms tentatively gravitate towards a particular approach Tentative go-ahead for the service	
LINE OF INTERACTION		LIN	NE OF INTERACTION	No. IIII	
TOUCH POINT ACTION	Greet Explain about Tapas Note down	Add to the Schedule Book the slot Send confirmation	Welcome the family Greet them Make them comfortable Offer them a tour of Tapas	Explain about Tapas - Home care - Tapas Elder Care Discuss primary symptoms and suggest best approach to take	
LINE OF VISIBILITY	LINE OF VISIBILITY				
BACKSTAGE ACTIONS	Prepare for engaging with the family Send first message for appointment	Prepare for engaging with the family Get the admission kit ready	Notify the concerned authorities Get the place of visit ready	Brochure to explain Message for primary CSI Assessment	
LINE OF INTERNAL INTERACTIONS		LINE OF I	NTERNAL INTERACTIONS		
SUPPORT ACTIVITIES, PROCESSES AND ARTEFACTS	First message for appointment	Tapas Schedule Confirmation message Admission kit	Welcoming Protocols		
DELIVERABLE	Deliverable #1	Deliverable #2 Deliverable #3	Deliverable #4	Deliverable #5	

16.2.1 Assess

STEP	Narration by Family	Plan of Assessment
STEP GOAL	First level of understanding of the symptoms	Schedule and plan further activities
USER ACTION	Explain by recalling the problems that the family is facing	Discuss availability and comfort in the activities
LINE OF INTERACTION		
TOUCH POINT ACTION	Note Down Ask Questions if any Probe deeper into finding problematic ares/ situations	Guage willingness, comfort and openness Schedule further activites
LINE OF VISIBILITY		
BACKSTAGE ACTIONS	Collect results for analysis	Prepare for further activities and visits Notify experts about the scheduled activities and visits
LINE OF INTERNAL INTERACTIONS		U.
SUPPORT ACTIVITIES, PROCESSES AND ARTEFACTS	Template for observations	Plan of Action Document
DELIVERABLE		Deliverable #7

16.2.2 Assess

QoL Assessment	Medical diagnosis	Observations by experts	Analysis of collected data
Assesing the Caregiver's Stress Index	Proper diagnosis for addressing the right issues	Understanding home settings and true situations	Analysing the collected data for selection of services
Fill the questionnaire	Get the tests done for the PlwD (might include visit to a clinic/hospital)	Show around the home Introduce to the PlwD	Recieve updates
LINE OF IN	TERACTION	**	
Administer questionnaire over mail/ message Collect reports Conduct tests (eg. neuro-psychoanalysis)		Note down observations	Update the family about analysis
LINEOF	VISIBILITY		
Collect results for analysis	Send for expert review and analysis	Send observations for expert analysis	Analysis by experts Suggesting services from the repository of services
LINE OF INTERNA	ALINTERACTIONS		
QoL questionnaire form	checklist of tests needed. Allied hospitals with tie-ups (eg. Jupiter)		
Deliverable #6	Deliverable #7	Deliverable #7	

16.3 Specify

STEP	Discussion of Analysis and Plan of Action	Explaining short and long term goals	Scheduling for a limited period of time (setting up time-table of experts)	
STEP GOAL	Sharing the insights and suggestions with the family	I Setting right evhectations Lecting/hillot		
USER ACTION	Share their feedback Share necessary details. eg. daily routine Share prima facie assessment	Understand, comprehend, convey expectations	Trying things and optimizing/stabilizing them	
LINE OF INTERACTION	LINE OF INTERACTION			
TOUCH POINT ACTION	Share insights Prepare plan of action	Explain the suggested services and outcomes Explain the roles of the family members	Trying things and optimizing/stabilizing them	
LINE OF VISIBILITY	LINE OF VISIBILITY			
BACKSTAGE ACTIONS	Consult experts, prepare resources on standby	Notifying concerned experts	Confirmation of schedule from experts	
LINE OF INTERNAL INTERACTIONS	Li	NE OF INTERNAL INTERACT	ions	
SUPPORT ACTIVITIES, PROCESSES AND ARTEFACTS		Update schedules		
DELIVERABLE	Deliverable #8	Deliverable #10	Deliverable #9	

16.4 Evolve

STEP	Completing scheduled activities	Assessing activities	Giving regular feedback	Analysis
STEP GOAL	Participation of the family	Compatibility of activities	Reporting	Improvisation
USER ACTION	Following instructions and conducting the activities mentioned at mentioned times Providing observations about the behavior of PlwD during the activities	Observing responses of the PlwD and noting down	Providing observations to the experts Sending log sheet images	Providing insights on what works and what does not works
LINE OF INTERACTION		LINE OF INTER	ACTION	
TOUCH POINT ACTION	Collect observation Analyse Infer	Collecting observations and analyzing	Recieving the logs Analysis	Analysing the observations Suggestion of changes
LINE OF VISIBILITY		LINE OF VISI	BILITY	
BACKSTAGE ACTIONS		Improvisations in the plan of action	Forwarding it to the experts	Improvisations in the plan of action
LINE OF INTERNAL INTERACTIONS	LINE OF INTERNAL INTERACTIONS			
SUPPORT ACTIVITIES, PROCESSES AND ARTEFACTS	Format for noting observations	Format for observations	Format for observations	
DELIVERABLE		Deliverable #9		Deliverable #8 Deliverable #9

17. Deliverables

Deliverable #1

Inquiry Call

- Greet
- Mention where the user has called: Eg. Hello, Tapas ElderCare
- Introduce yourself
- Listen carefully
- Ask about their PLWD, situation ...
- Ask if they want to know about Tapas
- Explain a bit about Tapas
 - Location
 - Two services:- residential care home and domiciliary care
- Invite to Visit

Deliverable #2

Deciding time to visit

Hello

This is **XYZ** from Tapas Elder Care.

Thank you for reaching out to Tapas Elder Care.

We invite you to visit our facility at Pashan, Pune. The purpose of the visit would be to explain to you about our services and facility and give you a tour of the same. We would like to know when you would like to visit. Please reply to this message with the date and time of your preference.

In the meantime, you can visit our website:

http://www.tapashealthcare.com/

Please feel free to reach out on a call if you need further assistance. I would be more than happy to speak with you.

Thank You

Guidelines:

The name of the person sending the message needs to be added for personalizing the message. It is better if the person who received the first call communicates further messages and takes up the responsibility of the entire inquiry process.

Deliverable #3

Confirmation of visit: After fixing the meeting Text message over SMS/ Whatsapp

Hello

This is XYZ from Tapas Elder Care.

Thank you for reaching out to Tapas Elder Care.

As decided over the call your appointment is fixed on

Date: xx/xx/xx

Day: XXXday

Time: XX.XX am/ pm

Venue:

https://goo.gl/maps/xN7XzC7N5keB21TZA

7/2/8, Ulka Residency, Krishna Nagar,

Near Sunny Sports Complex, Ward No. 8, Someshwarwadi,

Pashan, Pune, Maharashtra 411008

It is approximately a 25 minute (7.5 km) drive from Deccan Gymkhana. Pune

It is approximately a 30 minute (22 km) drive from Mumbai-Pune Expressway Exit

You can visit our website:

http://www.tapashealthcare.com/

Please feel free to reach out on a call if you need further assistance. I would be more than happy to speak with you.

Thank You

Guidelines:

The name of the person sending the message needs to be added for personalizing the message. The date, day and time should be added appropriately.

Deliverable #4

Greeting

Parking Instructions Board
Protocols for welcoming FPIwD

- 1. Unlock and open the gate
- 2. Greet FPIwD with a warm smile and correct designation and name
- 3. Introduce yourself
- 4. Ask how was the travel
- 5. If they have come in their own car, ask where they parked it.
- 6. Direct them to the right parking space if the car is parked in a problematic area
- Escort them to Prajakta Ma'am's office and direct them to a seat
- 8. Offer water (tea/coffee)
- Ask them if they need anything else. Let them be comfortable
- 10. Offer to take them on a tour of the place.
- 11. Hand out brochures.

Deliverable #5 Template for Primary Observations with checklist **Primary Caregiver's Details** Name: Relation with the person with dementia: Contact: Details about the Person living with Dementia Name: Age: Occupation: Symptoms observed Accusations Aggression Disinhibition Problems while Dressing Confusion while Eating □ Hallucinations ☐ Toileting Difficulties and Incontinence ☐ Difficulty in maintaining Personal Hygiene Repetition Shouting ■ Sleep Disturbance ■ Withdrawal and Non-Communication

Any other problems you have faced:

Deliverable #6

After Visit: tentative go-ahead for the service

Hello

This is XYZ from Tapas Elder Care.

Thank you for reaching out to Tapas Elder Care.

This is a short questionnaire that would help us assist you better. It will be really helpful if you could spare some time and fill it out.

https://forms.gle/9AKKEzgVRfA7TdJq5

Please feel free to reach out on a call if you need further assistance. I would be more than happy to speak with you.

Thank You

Guidelines:

The name of the person sending the message needs to be added for personalizing the message.

Deliverable #7

Plan of Action



Plan of Assessment

Assessment Type	Y/N	Date	Day	Time	Comments/ Special Instructions
Family Observations Taken					
Primary Observations Taken					
Expert Observations at Home					
Medical Reports 1. 2. 3.					

Deliverable #8

Repository and criteria for performance rating

Please rate the engagement level for the activities

1= did not comply at all to participate

2=complied but with a lot of persuasion

3=complied with a little persuasion

4=participated without response

5=participated willingly

6=participated eagerly and seemed to be enjoying

Please Remember:

The purpose of the activities is to engage the person and stimulate them. The process is to be focused on rather than the final output.

- 1. Music
- 2. Puzzles
- 3. Movie
- 4. Games
- 5. Pet Therapy
- 6. Craft
- 7. Painting
- 8. Cooking
- 9. Dance therapy
- 10. Reminiscence therapy
- 11. Events at Tapas:
- 12. Shopping
- 13. Visiting friends

- 14. Reading
- 15. Dusting
- 16. Assisting in kitchen
- 17. Watching old videos/ photos of family functions
- 18. Visiting an aquarium (snoezelen room stimulation)
- 19. Community prayers
- 20. Gardening

Deliverable #9

Template for logbook

Weekly monitoring of activities



Activity Schedule and Monitoring

Sr. No.	Date	Activity	Complete (Y/N)	Engagement 1 to 6	Additional Comments
1					
2					
3					
4					
5					
6					

Deliverable #10

Guidelines for family in the form of booklet

18. Service Failures and Recovery

18.1 Assessment is wrong

If the assessment done is not optimized, the care routine planned might not suit the PlwD. They might not enjoy the activities and might refuse to participate. The process of specifying resources and evolving the care routine is thus iterative. However, the PlwD losing interest in the activities will prove to be a setback and the next iteration will have to be more stringent and diligently done.

18.2 Activity session not happening well

If it is observed in the log sheets that the activity sessions are not happening as well as they should go on, it will be urgent and highly necessary to find out the cause for the same. If there is an issue from the family's side, it should be addressed immediately.

18.3 Delay in arriving on-site for activity session

Sometimes due to unforeseen conditions, the support staff may not be able to reach on-site for activity sessions. In such situations, the family should be informed as soon as possible and they may be compensated with extra activity sessions. However, delays and last-minute cancellations from the service provider's side should be avoided.

In case of emergencies, the support staff should stay online in contact while reaching on-site in order to assist remotely till they reach the place.

19. Contributions of the Service

In many households, primary caregivers like Shailesh and Aparna or Mrs. Narmada Sharma lose their calm and get frustrated due to the intense pressure the care puts on them. It is more or less a thankless job and requires a lot of patience. This service will help such caregivers meet their needs for professional support.

Caregivers like Aparna will be able to find time for their hobbies, physical and mental wellbeing. Being stress-free will help them lead a life with better quality. This will, in turn, affect the quality of care that the PlwDs will receive, thus improving the quality of life of the PlwDs.

This service will improve functional, emotional and social benefits.

Monetary and effort costs might increase, however, psychic benefits will be tremendous along with some reduction in time costs.

 $Value\ Equation = \ \ \, \frac{ \ \ \, Functional\ Benefits\ \uparrow + Emotional\ Benefits\ \uparrow + Social\ Benefits\ \uparrow}{ \ \, Monetary\ cost\ \uparrow + Time\ cost\ \downarrow + Efforts\ cost\ \uparrow + Psychic\ cost\ \downarrow \downarrow}$

20. Plan for Evaluation

The evaluation of the project will consist of three stages.

Expert Evaluation with Delphi Technique

Two rounds of the Delphi technique will be conducted. The first round will consist of experts reviewing the project and answering a questionnaire consisting of 10 objective questions and one open-ended question.

It will be followed by the second round where there will be a discussion amongst the experts based on their responses in the first round.

For forming the questionnaire, the VIPS framework for person-centered care for PlwDs in nursing homes (Brooker; 2004) can be used:

- V- A value base that asserts the absolute value of all human lives regardless of age or cognitive ability.
- I- An individualized approach, recognising uniqueness.
- P- Understanding the world from the perspective of the service user.
- S- Providing a social environment that supports psychological needs.

The composition of the panel of experts reviewing the project will be of people who have knowledge about caring for dementia.

Eg. Palliative Care Expert, Psychiatrist, Physician, Counsellor, etc.

To what degree does the proposed solution solve the problem? $\ensuremath{^*}$
Completely
○ Mostly
Partially
○ Not at all
What might cause hindrances for the families to implement this service according to you? * Financial causes
O Social Pressure
Resistance from other family members
Geographic limitations
Maintaining the motivation

Qualitative Assessment with families

A questionnaire will be administered to at least 3 families that have previously lived through or are currently living through the experience of caring for a person with dementia at home.

Expert Evaluation by Experts familiar with various kinds of services and business

A questionnaire will be administered to this group of 4-5 experts after presenting the service.

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Annexure

Consent Form:

STATEMENT OF INFORMED CONSENT

What is the study about?

The purpose of the study is to understand the interactions between different stakeholders in Tapas Geriatric Care to enhance the experience for caregivers and family/relatives. This study might also produce research papers and reports.

Who are the researchers?

Gauri Tillu: 186330002

Interaction Design, M. Des Student at Industrial Design Centre, IIT Bombay

How are we collecting information?

We will ask you questions regarding different experiences with/at Tapas. We will observe you interact with the doctor and staff at Tapas. We will record the interactions and we will take notes to record your comments and actions.

How do we ensure the confidentiality of the data?

The recordings will be treated as confidential and will only be shared with team members relevant to the project. We may publish research reports that include your comments and actions but your name and identity will not be revealed.

Your participation in this study is voluntary.

You can choose not to answer a particular question. You can discontinue/leave at any time without giving a reason.

Your consent

Please tick the relevant boxes to provide consent

- ☐ For people to observe you during the research.
- ☐ For the interactions to be recorded.

For people on the design team to watch the recordings in the future
I, (Full Name)
(please specify relation with patient/ Tapas Geriatric Care), have been informed and explained in good
faith that I will be subjected to this research study.
All the things mentioned above have been clearly explained to me/us and I/we confirm that I/we have understood the same.
Signature:
Date: Place:

Interview Guide:

Family Background(Ice Breaker)

- Number Of Members Of The Family, Ages
- Geographical Locations Of The Family Members
- Educational Background/
- Profession/ What and where do they work? Work time?

History Of Dementia(Awareness)

- When Was Dementia Diagnosed? How?
- Journey before diagnosis?
- Care Routine
- Primary Caregiver?
- Have they employed anyone? Qualification
- How Do You Organise Your Life Around The Care Routine
- · Why?

Pain Points

- Condition of Mobility Can they walk? Do they need to be carried?
 Who carries them? How?
- Sleeping habits Is your sleep disturbed? How often? Why?
- Any Aggressive Episodes Any Painful Situations
- How Did You Handle It? Why?
- How do you manage at home? Who stays with them? Does it cause any problems?
- How Often Do You Feel Stressed Out
- Reasons for the stress
- Have you had to take time off your work? How often?
- Have You Asked For External Help? Why?
- How much does it cost?
- They Must Be Required To Take A Lot Of Medicines. How Do You Manage That? Why?
- Do They Take Them Easily Or Does It Need Some Persuasion? How? Why?
- How Do They Remember Taking Medicine?

How much do you think they have changed from their former self?
 How is that affecting you?

Improvement And Progress(Expectations/Limitations/Awareness)

- How Do You Measure Improvement? Why
- Which Doctors Have You Consulted? Why
- What do they think is an ideal condition which will enable them to take care?

Caregiver's Stress Management Regime(Awareness)

- Have You Tried Talking To Anyone? Or A Support Group Perhaps?
 Why?
- Where Do You Unload Your Stress And How Do You Do It? Why?

Expert Review Questionnaire for Delphi Technique

- 1. To what degree does the proposed solution solve the problem?
- 2. What might cause hindrances for the families to implement this service according to you?
- 3. What do you like the most about our service?
- 4. What do you like the least about our service?
- 5. How would you rate the individual stages:
 - a. Engage
 - b. Assign
 - c. Specify
 - d. Evolve
- 6. Does the service take an individualized approach towards care?
- 7. Does the service understand the world from the perspective of the
- 8. Does the service aim to provide a social environment that supports psychological needs?
- 9. Does it leverage the players and resources in the ecosystem?
- 10. Has the balance between technology and human touch been achieved?
- 11. How likely are you to recommend our services to your friends/family?
- 12. Additional comments: