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SUCCESS

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KEY INFORMATION FROM 'DESCRIPTION OF WORK'	
DELIVERABLE DESCRIPTION	To identify needs, requirements and the context of the use, an ethnographic study will be conducted in Austria and Romania. Researchers will observe and participate in the life of informal caregivers and the working practice of formal caregivers for two days to gain extensive insight into their (social) practices and requirements. A subsequent user and expert workshop will complement the participant observation as it allows to validate and deepen the insights and initiates the co-design process. The detailed methodology and the results will be reported in in this deliverable.
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ABBREVIATIONS

ABBREVIATIONS	DESCRIPTION
AAL	Active and Assisted Living
AAL CMU	AAL Central Management Unit
PwD	Person(s) with Dementia

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AAL PROJECT SUCCESS

In the European research project SUCCESS (SUccessful Caregiver Communication and Everyday Situation Support in dementia care), an innovative mobile training application is being developed. It aims at supporting caregivers of people with dementia (PwD). The users of the application are introduced to evidence-based communication and intervention strategies by reading articles, engaging in conversations with an avatar, and listening to lectures presented by an avatar. This format of learning and the multimodal user interface of the app supports different usage situations and contexts. All implemented features are believed to increase the quality of communication and interaction of care persons with PwD and minimize burden of care. This is done by fostering a deeper understanding for PwD (e.g. understanding why PwD can become aggressive) and supporting the caregiver with useful situation-related suggestions. A remarkable feature of the app is that it is not only focusing on the relationship between the caregiver and the PwD and the behaviour of the PwD, but on the caregiver, too. This is done by highlighting the importance of self-care among caregivers and implementing a meditation and diary feature. SUCCESS supports the PwD to maintain a purposeful life by suggesting meaningful activities that can be adapted to various stages of dementia. Additionally, the app provides a quick help feature and the possibility to personalize the content by using tags. Therefore, SUCCESS is an application that caters to every stage of dementia and supports caregivers in various situations by providing information, a possibility to apply and train the gained knowledge, and tools for self-care.

The research presented is conducted within the SUCCESS project (AAL-2016-089), partially funded by the European Active and Assisted Living Programme and the National Funding Agencies from Austria, Cyprus, Norway and Romania.

EXECUTIVE SUMMARY

This deliverable describes the aim and methodology of both the ethnographic observations, including the ethnographic interviews, and the expert workshops/interviews. Those studies are done in Austria and Romania, conducted by the partners EUR, AIT and RAS.

During the ethnographic observations, formal and informal caregivers of PwD will be observed and interviewed. Getting to know the caregivers' everyday challenges when caring for a PwD will help us to define and refine the SUCCESS scenarios. Those scenarios will further be evaluated, discussed and refined through workshops/interviews with dementia experts.

In the expert workshops we will evaluate the current status of the SUCCESS plans with dementia experts in Austria and Romania.

The results of the ethnographic observation and the expert workshops/interviews will be described in an iterated version of D2.1.

1 ABOUT THIS DOCUMENT

1.1 ROLE OF THE DELIVERABLE

This deliverable serves as common document for the methodological conduction and analysis of the ethnographic observations, including the ethnographic interviews, and the expert workshops/interviews in Austria and Romania. It further summarizes the results of the evaluations.

1.2 RELATIONSHIP TO OTHER SUCCESS DELIVERABLES

The deliverable is related to the following SUCCESS deliverables:

DELIVERABLE	RELATION
D1.4 Ethical guidelines and manual	The methodology of the ethnographic study and the co-design workshop rest on the ethical guidelines described in D1.4.
D2.2 Use Cases, Scenarios, Service and Interaction Design Concept	The Use Cases, Scenarios and the Service and Interaction Design Concept will be defined upon the results of the Ethnographic study and the co-design workshop.
D3.3 Learnings and role-play approach	Learnings and role-play approaches will be defined upon the results of the Ethnographic study and the expert workshops.

1.3 STRUCTURE OF THIS DOCUMENT

Chapter 2 describes the aim and methodology of the ethnographic observation including the research questions to be answered, the study procedure and the results of the ethnographic observations.

Chapter 3 describes the aim and methodology of the expert workshops/interviews including the research questions to be answered, the study procedure and the results of the expert workshops/interviews in Austria and Romania.

Appendix A presents the observation protocol for the ethnographic observations.
Appendix B describes the interview guide for the ethnographic study
Appendix C presents the interview guide for the expert workshops/interviews.

2 ETHNOGRAPHIC OBSERVATION AND INTERVIEWS

2.1 AIM OF THE ETHNOGRAPHIC STUDY

The first activity, understanding and specifying the context of use, involves identifying users and tasks, and describing the environment. Thus, relevant questions to investigate are: Who are the users? What are typical tasks and goals associated with the use of the system? What are characteristics of the social and physical environment and (social) practices? In the context of SUCCESS, an ethnographic study including participant observation studies (visits to care homes of PwD) and ethnographic interviews will be performed. Additional workshops/interviews with experts will validate the evolved insights (see chapter 3). Specifying the user requirements involves elaborating and structuring this information. Thus, relevant questions include: What are the specific needs of the primary and secondary users? What are the specific needs derived from jointly considering the user and the social and physical environment?

To identify needs, requirements and the context of use, an ethnographic study will be conducted in Austria (led by EUR) and Romania (led by RAS). We will observe and participate in the life of informal caregivers and the working practice of formal caregivers for two days (excluding the night) to gain extensive insight into their (social) practices and requirements. EUR and RAS will contact formal and informal caregivers related to defined care homes asking for permission to accompany them. A subsequent user and expert workshop will complement the participant observation as it allows to validate and deepen the insights and initiates the co-design process.

Three informal and three formal caregivers and two experts for dementia will participate per trial site. The detailed methodology and the results will be reported in D2.1.

Aim	Method	Users	UCD activity
Understand (social) practices; Identify real needs, services & their functions requested	Ethnographic study (participant observation, ethnographic inquiries) and user and expert workshop	each 6 (in-)formal caregivers in AT and RO / each 2 dementia experts in AT and RO	Understand context of use, specify the user requirements, produce design solutions

2.2 RESEARCH QUESTIONS TO BE ANSWERED

Main research aim: Research how caregivers react in stressful situations with PwD to derive support mechanisms integrated in the SUCCESS app.

a) How does a **typical day** of an informal and formal caregiver look like?
b) What are the **tasks** of an informal and formal caregiver for a PwD?
c) How do the caregiver and the PwD **interact**?
d) How do they **cope** when overwhelmed? What do they do in these situations? How do they manage/overcome such situations?

e) In which aspects of care for PwD do caregivers mostly need **support**?
f) Which kind of **emotional** support do caregivers need in which care situations?
g) Which kind of **practical** support do caregivers need in which care situations?

Interview questions
h) What are the **requirements** for caregivers to use ICT-based support?
i) **In which situations** would informal and formal caregivers like to do trainings with an ICT-based device?
j) How should the training content or advice differ according to the care **situation**?
k) How should the training content or advice differ according to the **relationship** between the PwD and the caregiver (husband/wife, son/daughter, son/daughter-in-law, registered nurse, etc.)?
l) How do caregivers experience the concept of an Avatar 'having' dementia to interact with in the role plays?

2.3 METHODS

2.3.1 MATERIAL NEEDED

- Signed agreement of the institution (care home, hospital, etc.)
- Informed Consent
- Observation protocol
- Interview guide
- Questionnaires (for sociodemographic data)
- Camera (e.g. GoPro; for taking photos of the environment (not PwD) If caregiver does not agree in informed consent, observer should make at least a sketch of the surrounding to see relations between people and things in the environment)
- Voice recorder (for the interview at the end; Smartphone, etc.)
- Reimbursement
- Reimbursement form

2.3.2 PARTICIPANTS

In total, 12 people will be involved in the study, both formal and informal caregivers. We aim to involve both female and male caregivers of PwD. However, as there are more women caring for PwD, we will not be able to balance the participants in terms of gender. There are no inclusion criteria based on the age of participants, but we will not involve people that are younger than 18 years. Each six people will be involved in Austria and Romania. The rate of informal and formal caregivers will be kept flexible according to the possibilities to participate also in informal caregivers' everyday life. It is assumed that formal caregivers are more willing to agree to participate in their care activities. The aim is to balance the number of formal and informal caregivers in the study.

Involved **informal caregivers** are family members or natural persons who aid and supervise for a person living with dementia, as for example the husband/wife, daughter/son, daughter/son-in-law, mother/father or a friend.

Involved **formal caregivers** are people that professionally care for a person living with dementia (as an occupation). Thus, they have some kind of medical background but not necessarily are trained to care for a PwD. Formal caregivers involved in the study may work for example in a care home, hospital, day care center or even as professional caregiver in a PwD's own home. In course of the ethnographic study, they should care for at least one PwD but could additionally care for other people not affected by dementia.

2.3.3 REIMBURSEMENT

Participants of the study will be given a reimbursement in the amount of 80 Euro in Austria and 80 Euro in Romania for their time efforts in participating in the study. The costs for reimbursements are taken over by EUR/AIT in case of Austrian participants and by RAS in case of Romanian participants.

2.4 STUDY PROCEDURE

PROCEDURE	DURATION
EXPLAINING AIM AND METHOD OF THE STUDY	10 min
INFORMED CONSENT	5 min
ICE-BREAKING INTERVIEW	15 min
OBSERVATION	12 h (in total)
POST INTERVIEW	30 min
GIVING THANKS, REIMBURSEMENT, FAREWELL	10 min
TOTAL	**13h 15min**

Table 1: Study procedure

2.4.1 INFORMED CONSENT

Article 17 of the Protocol to the Convention on Human Rights in Biomedicine or Biomedical Research states: "No research on a person may be carried out without the informed, free, express, specific and documented consent of the person".

This places a legal obligation on observers to obtain and record consent from participants or their guardians, on the basis of information that should be given to them before their participation begins. In the present project, all participants will be asked in advance to state by signing an informed consent form that they are fully aware of the experimental procedure, the potential risks or benefits (if any) and that their participation is completely voluntary.

Participants must be given the right to withdraw from any given research, at any time without penalty and without providing reason. Participants can also require that their data will be withdrawn from the study and destroyed.

There will be arrangements for safe and straightforward cessation of use by an individual who initially agreed to participate but later decides to withdraw from the study.

Informed consent forms will include all subsets of the following details:

- that the project involves research,
- overall purpose of the project,
- experimental procedure,
- potential risks and benefits,
- inclusion/exclusion criteria,
- the person to contact for further information regarding the project
- the rights of project subjects,
- whom to contact in the event of project related injury,
- planned use of the data,
- possible commercial exploitation.

2.4.2 ORGANIZATIONAL APPROVAL

Additionally to the Informed Consent of participants, we will ask the organization of participants for their signed approval to conduct the study in their organization. This procedure only applies for participants who are formal caregivers.

The organizational approval forms will include all of the following details:

- that the project involves research,
- overall purpose of the project,
- experimental procedure,
- potential risks and benefits,
- inclusion/exclusion criteria,
- the person to contact for further information regarding the project
- the voluntary participation of their employees based on their signed informed consent
- planned use of the data,
- possible commercial exploitation.

2.4.3 ICE-BREAKING INTERVIEW

At the beginning of the observation, the observer will conduct a short interview (about 15 min) with the participant. The interview is based on a semi-structured interview guide (see Annex II). This means, the evaluator does not have to strictly stick to the questions and their order but should try to get participants' views on all involved aspects of the interview guide. The interviews are voice-recorded to allow the evaluator to play back participants' comments at a later stage. Additionally, the evaluator will take notes from the participants' comments in the evaluation spreadsheet.

2.4.4 ETHNOGRAPHIC OBSERVATION

Duration

The observation will take altogether about 12 hours per participant. The observation time can be adapted to the individual participant. It is assumed that the participation in the lives of informal caregivers will be done in smaller time units of about 1 to 2 hours, since, from the experience of the experts, a foreign person (=observer) in a private home affects the informal caregiver (and also the PwD) more than a formal caregiver in an institutional setting.

- e.g. Monday 9h to 12h, 1 h break, 15h to 18h; Tuesday 7h to 10h
- e.g. Monday 9h to 12h, Wednesday 13h to 16h, Thursday 12h to 15h

The aim is to observe care sequences of different times of the day between 7h and 19h to observe different aspects of care:

- Morning hygiene
- Dressing up
- Medication
- Breakfast
- Before midday activities
- Lunch and coffee
- Afternoon activities
- Dinner
- After dinner activities
- Getting ready for the night

During those care activities, the observer will respect privacy and intimacy of the PwD, thus, will not observe the care activities while the PwD is naked, on toilet or in similar intimate situations.

Observation protocol

It can be quite difficult to observe, and take notes simultaneously, and sometimes it can be distracting to those who are being observed. However, when the opportunity presents itself, the observer should attempt to record the observations while carrying out the observations. However, if the ethnographic setting does not allow to take notes while observations are conducted, then the observer is advised to make sharp mental notes, and to record their field notes immediately upon departing the setting observed (Whitehead, 2006).

Observers usually make their detailed field notes in three steps: (1) During observing, scribbled cues as quick reminders are noted. By this, the disruptive factor of recording is minimized for the observed person as well as the observer. (2) In the next step, the scribbles have to be expanded. Use every opportunity and pause of interactions to add more detailed notes. Add as many quotes as possible. Keep the defined relevant categories (see below) in mind. (3) The actual production of the field notes starts outside of the field. 'Outside' refers to the field's physical and social characteristics. Usually, observers record at the evening after returning home or to her/his office. Try to reconstruct the observations as detailed as possible and note everything.

Please note, that the three levels of comprehensiveness exist side by side; the third step does not replace the first and the second.

Besides the empirical notes, methodological and role reflexions have to be recorded.

The observation protocol consists of three parts:

1) **General information of each observation session**

At the beginning of each observation session, the observer notes general information such as date of observation, name of observer, beginning time of observation.

To give an impression of the situation of the observation, the observer takes notes about the social setting and physical environment as well as space and objects in the setting. Additionally, some characteristics of the people (actors) involved in the setting are noted. A detailed explanation of these categories is described in the table below:

CATEGORY	DESCRIPTION
THE SOCIAL SETTING/ THE PHYSICAL ENVIRONMENT	Includes the various attributes of the scene, which is being observed or studied (e.g. Care home, hospital, private home, etc.). For example, if the setting is a building (e.g., a hospital), one may want to record size, physical features, the internal organization of the hospital (i.e., where various rooms are situated), and the location of the room in which the particular scene being observed takes place. If the setting is an outside venue (e.g., a street corner, a park, a playground, etc.), the observer may want to record how the area looks, what is inside the setting, and what surrounds it, or is found in the immediate vicinity or proximity.
SPACE AND THE OBJECTS IN THE SETTING.	Here we are returning to the inside of the setting being observed and observing the layout of the space in which the act, activity, or event that is being observed, including specific objects. The observer may also want to assess whether the objects might have any specific meaning. For example, within a religious setting, there may be numerous objects that have powerful symbolic meanings. But meanings may also be found in the way the room in the church in which the act, activity, or event being observed is situated, such as the elevation of the pulpit, where the choir sits, etc.

Table **2**: Categories for taking notes on general information of an observation session

2) **Notes of scenes**

Each scene should have a heading describing a title and time of the scene.

The observer should incorporate the following aspects when making the notes:

- Actors in the setting
- Actor groups
- Interactive Patterns
- (Non-)Verbal Language
- Individual Behaviour carried out by actors
- Goals, Motivations or Agendas
- Emotion

A bookmark with the categories described can be used as a mental reminder during the observation. Each category is described in the following table:

CATEGORY	DESCRIPTION
TITLE OF SCENE	e.g. Breakfast, Afternoon activity, PwD starts screaming
TIME OF SCENE	What is the time of day, day of the week, time of the month, and month or season of the year that this setting is being observed?
ACTORS IN THE SETTING	Record the number of people in the setting. Then describe those people, in terms of such characteristics as sex, age, ethnicity, height, weight, skin colour, and other general features that might have some significance in understanding behavioural interactions. You should give each actor a pseudonym or a ID number (beginning with 001), as this may be someone you may have future opportunities to observe or interview.
ACTOR GROUPS	Are there ways that the actors in the setting are related, linked or differentiated?
INTERACTIVE PATTERNS	... between the actors in the setting, including patterns of dominant and subordinate personality, i.e., do certain actors seem to defer to or be controlled by other actors? Or are there compatible behaviours or opposing behaviours between one or more set of actors? Are there actors who seem to facilitate or instigate a particular type of behaviour between the set of actors.
(NON-)VERBAL LANGUAGE	Verbal: Is the event, and activities and/or acts being carried out in a particular language? Do communication breakdowns seem to be occurring because of language differences? In general record comment from participants that strikes observer as interesting, curious etc. (E.g. content (what is said); participation (who said what for what audience); method (how something is said, i.e., low/high volume and clarity)) Non-verbal: Observe and record any gestures or other forms of non -verbal behaviour that might have some relevance to interactions in the setting.

INDIVIDUAL BEHAVIOUR CARRIED OUT BY ACTORS	Observe and record specific behavioural acts that are taking place at the event. If possible include characteristics of behaviour that might have meaning. For example, did the behaviour appear animated, tense, stiff, lackadaisical, etc.
GOALS, MOTIVATIONS, OR AGENDAS	Note whether you think various individual actors or groups of actors seem to have specific goals, motivations, or agendas with regards to the event or activity being observe.
EMOTIONS	Do behaviours seem to be carried out with any level of emotions or feelings?

Table 3: Categories for taking notes on observation scenes

3) **Reflexion of observer**

This log includes reflections upon the temporal and social aspects of the ethnography as well as on the subjective impressions. Observers notice how they worked and which problems, irritations as well as coincidences occurred. Possible aspects of the log are the description of how the observer managed the field access, which relationships have been established and the quality of the relationships, which conflicts occurred, and which decisions have been made including what worked out and what did not work out. Reflections upon the social role of the observer and its development are of special importance because they allow an appraisal of the influence of the observer's presence in the field as well as the assessment of the subjectivity and the observer as an active part of the field. The observer her-/himself is the 'recording device' during the field phase and if immersion is successful, her/his experience are a major and valuable part of data acquisition. Methodological reflection upon the relevance of the observer's feelings differ. However, even though the focus of the study is on the field not the observer, emotions can provide invaluable insights in group dynamics within the field.

2.4.5 POST INTERVIEW

At the end of the observation, the observer will conduct a short interview with the participant. The interview is based on a semi-structured interview guide (see Annex II). This means, the evaluator does not have to strictly stick to the questions and their order but should try to get participants' views on all involved aspects of the interview guide. The interviews are voice-recorded to allow the evaluator to play back participants' comments at a later stage. Additionally, the evaluator will take notes from the participants' comments in the evaluation spreadsheet.

2.4.6 DATA ANALYSIS

The qualitative data gathered during the interviews and the observations will be analysed using Grounded Theory. Data for a grounded theory can come from various sources including interview data and observations. Both data will be coded in the same way. The methodology is based on Corbin and Strauss (1990) and described in their paper 'Grounded Theory Research: Procedures, Canons, and Evaluative Criteria'.

2.4.7 DATA MANAGEMENT

According to the EU data protection and privacy regulations, people have the right to protection of their privacy and personal data. The right to privacy entitles everyone to respect for his or her private and family life, home and communications. The right to data protection entitles everyone to the protection of personal data concerning him or her.

The user's personal data in SUCCESS is processed fairly for specified purposes and based on the consent of the person concerned or some other legitimate basis laid down by law. SUCCESS also guarantees that every participant has the right to access data, which has been collected concerning him or her, and the right to have it rectified. The right to privacy includes the right to control personal data. That is, the user must be aware of the data, the time period for which they are stored, and people who have access to the information. Further, the user has the right to object to the data processing.

For the ethnographic study in SUCCESS it is a simple policy whether to generally allow or not allow any data to be generated during the observation and the interview. However, participants can decide if they are further willing to be photographed by the observer. Disagreeing to be photographed is not an exclusion criterion of the study.

2.4.8 ACCESS TO DATA

Within this study, only employees of the respective organization that conducts the study will have access to the raw data. These are employees of RAS in Romania and employees of AIT in Austria. It is stated explicitly that data will be transferred from one partner to another within the consortium only after it was made anonymous. That means AIT (and the rest of the SUCCESS consortium) will only get access to anonymized data from the study conducted in Romania and RAS (and the rest of the SUCCESS consortium) will only get access to anonymized data from the study conducted in Austria.

2.4.9 TYPE OF DATA

There are four categories of user related data in SUCCESS:

a) Observational data: notes written by the observer about what the participant is doing and saying and descriptions about the situation and surrounding as a whole.

b) Interview data: notes written by the observer and audiotapes of the interview in case the participant agreed to be audio recorded during the interview.

c) Sociodemographic data of the participant: age, gender, job role, city of residence

d) Photographs: Photographs will only be taken by the observer in case the organization AND the participant agree in the informed consent that pictures are taken during the observation. The aim of the photographs is to get an impression of the surroundings (the room, objects in the room, etc.). In case it is useful to make pictures of situations with people involved, the observer will avoid making pictures of patients' and other people's face (other nurses etc.). In case other than the participant's faces are recognizable on pictures, they will be blurred before passing them to other partners of the consortium. If the organization or the participant do not agree in the informed consent that pictures are taken, the observer will make at least a sketch of the surrounding to get an impression of the environment.

2.5 RESULTS OF ETHNOGRAPHIC OBSERVATIONS: INFORMAL CAREGIVERS

2.5.1 OBSERVATION 1: INFORMAL CAREGIVER'S HOME IN VIENNA

General information of the observation session

Time of observation: Saturday, 4th and Sunday, 5th of November 2017, 9AM – 6 PM

Researcher: Kaan N. Özemek

Social setting and physical environment: The observation was carried out at a patient's private home. The apartment's size was about 70 m^2. The patient was living with his wife in a two bedroom-apartment located in the fourth floor of a condominium equipped with an elevator. The apartment is located in a relatively green area in the southern part of Vienna, a traditional working-class district.

Space and the objects in the setting: In the living room (about 25 m^2), there was a large bookshelf covering an entire wall of the room, there were two couches, a television set and a round table with a PC on it. The observer noticed that there were many framed photographs of the couple in the living room. The bookshelf was teeming with books and with board games. There were two doors in the living room, one leading to the kitchen and the other to the hallway. The bedroom (about 25 m^2) was furnished with a double bed and a cupboard. The small kitchen (about 12 m^2) had a refrigerator, a dishwasher, a stove and cupboards but no kitchen table. The bathroom had a bathtub, a sink and a toilet and was equipped with grab rails fixed on the walls next to the sanitary facilities.

Actors in the setting: Mr. M. (born 1940) and his wife (born 1942). Mr. M. has been diagnosed with dementia and Parkinson's disease six years ago. During the week, Mr. M. spends his days from 9:30 AM to 4 PM at a day care center for dementia patients. In the evenings and on weekends, his wife takes care of him. Mr. M. is overweight, about 1,80 m tall and he can only walk short distances and usually relies on his wheelchair to get around the apartment. His wife is 1,75 m tall, very thin and she struck the observer as a very dynamic, optimistic and vivacious woman.

Twice a day (in the morning and in the evening) one or two professional caregivers from Vienna's 'Heimhilfe"-program come to the M.'s apartment and help Mr. M. with personal hygiene and dressing. Because of her husband's weight, Ms M. cannot do this anymore for him.

Interactive patterns: Ms M. takes care of her husband and therefore assumes the dominant role in their relationship. She organizes their daily routines and keeps him entertained by reading the newspaper to him, by playing board games with him, watching television and listening to music. She has the full responsibility of her husband and herself as they have no children.

Non-verbal language: Due to the advanced stage of his dementia (5 MMST), Mr. M. has almost lost his ability to speak. He is only capable of giving brief answers to his wife's questions and sometimes asks her short questions. Ms M. has adapted to her husband's verbal impediment and next to speech she uses non-verbal cues to communicate with him. When she asks him something or when she talks to him, she caresses him, which seems to comfort Mr. M. but might also be a way for Ms

M. to establish an emotional connection that compensates for their fading intellectual connection. The non-verbal language between the M.s is very loving, kind and respectful.

Goals, motivations or agendas: Ms M.'s main motivation in taking care of her husband is for him to feel at ease and for the both of them to enjoy their life together. Because of her optimistic attitude, she is trying to make the best out of her situation, i.e., living with a spouse who suffers from severe neurological degenerative diseases. On weekdays, she is by herself during the day and has time to meet friends and to pursue her own interests. On the weekends, she spends time with her husband and from what I have observed, they have a good time together.

Emotions: Overall, the M.'s relationship is characterized by a lot of mutual respect, kindness, calmness, harmony and love.

Sources of knowledge and opportunities for counselling: Ms M. has acquired the knowledge she needs to take care of her husband through books, in particular about the maieutic care model by Cora van der Kooij. She also learned a lot about the care of dementia patients through the interaction with the caregivers who visit their home twice a day. Furthermore, she uses the Internet as a source of knowledge.

Meals: During the week, the caregivers visit the M.'s home at 7:45 AM. After they have helped him shower, go to the toilet and get dressed, Mr. M. drinks a cup of tea or coffee with his wife. Then, a transport service picks him up from home and takes him to the day care center, where he will be served breakfast. On weekends, the M.s have breakfast together at around 8:30 AM.

The M.s dine together every day at around 6:30 PM. Ms M. prepares the food, and she has to cut her husband's food in small bites and he has to drink liquids using a straw.

Afternoon activities: Ms M. does her best to entertain and stimulate her husband. Their afternoon activities include playing simple children's board games such as Ludo, watching television, listening to music (Mr. M. used to sing in a choir) and reading (Ms M. reads the newspaper and books to her husband). Ms M. also takes Mr. M. for a walk around the block every afternoon.

Challenges for caregiver: With her progressing age, it becomes increasingly difficult for Ms M. to take care of her husband and she could not do it without the aid of the 'Heimhilfe'-program. Still, her daily life with her husband suffering from dementia bears enough challenges. For instance, Mr. M. occasionally wakes up at night and is convinced that they have to go to a demonstration, something that they used to do a lot in the past when they were both politically active in Vienna's left-wing scene. On these occasions, Ms M. has learned that it is best to pretend that she will accompany her husband to the demonstration and that he will eventually realize that he was only imagining the situation. Also, the fact that Mr. M. sits in a wheelchair is mainly a physical challenge for Ms M. because she often has to lift him to overcome obstacles and with his weight and her age-related weakness, it is a huge strain for her. Mr. M.'s diseases dominate Ms M.'s life and to a large extent, her husband's illness dictates her lifestyle. While she is able to maintain her normal routines during the week when Mr. M. is at the day care center, they cannot travel together anymore as they used to in the past.

Reflection of observer and methodology: Ms M. gave the observer a warm welcome and was intent in making him feel comfortable in their home. When the observer entered the M.'s flat, Ms M. invited the observer to sit down with the two of them in the living room and they had a cup of coffee. They chatted a bit, got to know each other and Ms M. asked the observer about himself and his background. Nevertheless, initially it was inevitable for the observer to feel like an outsider, after all he was a complete stranger spending two days with them, observing their daily routines in the most intimate setting imaginable. After a couple of hours however, Mr. and Ms M. slowly got accustomed to his presence and he also felt more at ease and less as an intruder.

In general, it is very important to be able to communicate clearly the purpose and goals of the research to the observed participants as this helps build trust. In contrast to the participant observation at the day care centers, the confined setting at people's home makes it more difficult for the observer to operate in the background, figuratively speaking. On the other hand, the fact that the observer only had to focus on one patient made it easier for him to notice details that had slipped his attention at the day care center, where there were more people.

Seeing the participant observation in its overview, the research conducted at the M.'s was easier and a lot less complicated than expected. The slow pace of their daily life gave the observer enough time to take notes while he was there and he did not have the feeling that he could not keep up with what was going on. He did not feel uncomfortable in their home, quite the contrary, he thinks that for Ms M. his presence was a welcome distraction from her otherwise monotonous life with her husband. Ms M. was very open in the interviews she and the observer conducted throughout the course of the two days the observer spent with her and her husband. Even after the interviews were over, she told the observer a lot about her life. The observer thinks that she perceived him as a semi-professional actor and saw the conversations with him as a mix of counselling and exchange among peers.

Discussion: Mr. M.'s health condition is not good: his neurological degenerative diseases alienate him from himself and his surroundings, he is bound to a wheelchair and he is overweight. But thanks to his wife's relentless optimism and her calm stoicism in face of adversity, he leads a tranquil life and as far as the observer could tell in the two days he spent with them, he seems to be a happy man. Ms M. approaches her husband's disease not as a burden but as a challenge. She actively seeks to gain more knowledge about his condition, asks the caregivers from the 'Heimhilfe'-program for their advice and searches for more guidance online. Also, her participation in this study testifies to her pro-active attitude: even though she did not receive any money for taking part in the research, the observer thinks that in the end she will profit from participating because it gave her a sense of personal validation, a break from her routine and some new social contacts.

2.5.2 OBSERVATION 2: INFORMAL CAREGIVER'S HOME IN RUMANIA (MS V.)

General information of the observation session

Period of observation: 06.10.2017 – 18.11.2017

Researchers: Raluca Sfetcu (RS), Elena Dobrica (ED)

Social setting and physical environment: Ms M. is the niece (the daughter of her sister) of Ms V., who is now a widow. Ms V. married young but never had any kids. She lived her life as a housewife and had a long and happy marriage. Her husband died 5 years ago and ever since she is living alone. Since her husband died, Ms M. started visiting once a month to help with administrative issues. However, one year ago she started noticing Ms V. changes in her aunt's behaviour, which led her to bring her to RAS MC for a psychological consultation. After going through the examination procedure, Ms V. was diagnosed with dementia. Subsequently, Ms M. started to visit Ms V. on a weekly basis and to take over more of the tasks of Ms V., such as shopping and basic maintenance. Recently, Ms M. was on holidays for a week out of Bucharest. When she visited Ms V. on her return, she found her very weakened and, by checking the fridge she realised that Ms V. ate very little if anything in the passing week. She admitted her to hospital where she was treated and put on a regime. Now Ms V. just got out of the hospital and is living with Ms M. 's parents until her full recovery.

Space and the objects in the setting: Ms M. 's flat: a small but cosy and recently renovated 2 room apartment at the 6th floor of an eight stores block of flats in Berceni. Ms M. 's parents flat: a 3 rooms apartment in the same block and on the same floor as Ms M. 's flat. Most of the observation time is spent in the living room of Ms M. 's flat, a room of approx. 20 m^2, recently renovated which includes: a couch and a large sitting puff, a coffee table, large bookcase, cabinets.

Actors in the setting: Ms V., Ms M., R.S., E.D.

Interactive patterns: R.S. and E.D. arrive at M.'s place and are welcomed in the living room. R.S. introduces the project and explains the procedure to M. M. gives her consent to participate in the study; a brief interview follows. Ms M. started the discussion by telling us about the recent events in Ms V.'s life (not eating which resulted in a hospital admission to hospital) and Ms V. half-jokingly replied that she was doing that to embarrass her. This led to a conversation about the recent events and the plans for the future. Other topics discussed included a possible future visit of Ms V. to her relatives in Maramures, Ms V. 's apartment and her neighbours, Ms V. 's social interactions with neighbours and 1 male friend from childhood. R.S. and E.D. asked and intervened only minimally by addressing questions or making short comments. After a while, Ms M. invited R.S. and E.D. to her parent's flat where we visited Ms V.'s room and met Ms M.'s father.

Verbal and non-verbal language

Ms M. speaks articulately about her aunt Ms V. She talks about the life of Ms V. and her relationship to her by using a mix of appreciative and pejorative terms (e.g. trufanda, babeta). She now and then uses irony and humour to spice her story. The interaction between the 2 ladies is warm and familiar. Ms V. smiles and has a good disposition. They sit close to each other and touch often. Ms M. tries all the time to make Ms V. as comfortable as possible (for example by placing a pillow behind her). Several times Ms M. calls Ms V. "babette" and Ms V. smilingly opposes the term.

Goals, motivations or agendas: Ms M. is the sole career of four older adults (her mother and father, Ms V. and Ms V.'s husband – until 5 years ago). This also makes her the only inheritor of her family.

Emotions: mixed feelings of affection and slight annoyance.

Sources of knowledge and opportunities for counselling: Ms M. searched for information on the internet and from health services she has been in contact with while caring for her aunt. For a short period of time she also volunteered in the MC of RAS. When she needs advice she contacts the activities coordinator at the MC of RAS.

Day structure: Ms V. currently lives alone in her flat. Her daily structure includes a small breakfast, taking a short walk around the building in which she lives, watching TV, interactions with neighbours and talking on the phone with her niece or sister. Ms M. visits her twice a week to buy groceries, organize the medication and care for the other needs of Ms V.

Challenges for caregiver: The main challenges for Ms M. are represented by psychological and behavioural symptoms such as: repetitions, refusal to eat certain types of food and suspicion of having stolen certain objects.

2.5.3 OBSERVATION 3&4: INFORMAL CAREGIVER'S HOME IN RUMANIA (MR. B)

General information of the observation session

Period of observation: 12.10.2017 – 15.11.2017

Researcher: Raluca Sfetcu (RS)

Social setting and physical environment: Mr. B. is living at home with his wife Ms B. in a three rooms apartment in the centre of Bucharest. He refuses care from other persons with the exception of a cognitive stimulation specialist who visits him twice a week (F.V.). Mr. B. has been diagnosed seven years ago and has a MMSE score of 9. He spends most of his day in bed and has not left the apartment for several years. He has a high number of physical comorbidities (diabetes, CVA, etc) and a high level of dependency. Cognitive stimulation sessions last around 2 hours and consist of a number of activities such as: doing puzzle, playing cards or completing cross-words. These activities are interrupted by short sessions of light physical exercises.

Space and the objects in the setting: The observation sessions took place in Mr. B.'s room (transformed from the living room at the participant's request) and the interview took place in a large lobby (first room after the entrance in the apartment). The room is around 30 m^2 and it includes: an extended couch, two small tables (on one of them an old TV set and on the other table an old model of a radio), a large dinner table with four chairs around it, bookshelves and several paintings hanging on the walls.

Actors in the setting: Mr. B., Ms B, F.V., R.S.

Interactive patterns: During most of the time the observer spent at Mr. and Ms B.'s home, Mr. B. was in his room, watching TV or resting. Interactions with his wife were short and purposeful, being prompted by the evaluation of Ms B. that her husband might need support with something (e.g. using the toilet). As Ms B. has few opportunities of social interactions, she is happy to converse with the observer and to share details of her life together with her husband. In the meantime, F.V. is engaging the patient in stimulating activities.

Verbal and non-verbal language: The hearing of Mr. B. is poor and Ms B needs to heighten her tone of voice whenever she speaks to Mr. B. She uses short sentences, but her voice remains calm, warm and respectful at all times. Ms F.V. uses short instructions and repeats information whenever necessary.

Goals, motivations or agendas: Ms B. feels very appreciative for a long, happy and respectful marriage and believes it is her duty to provide as much dignity as possible to her husband, even if the caring process places a high burden on her shoulders.

Emotions: Ms B. uses a warm and calm voice at all times when speaking to her husband. In relation to the observer, Ms B. cries as she recalls different episodes of her life with her husband and also when providing details about their current life. The caring process is perceived as burdensome and the social isolation derived from the caring situation (Mr. B.'s state - among other things, Mr. B. is also incontinent - has determined Ms B. to reduce the number of visits she receives).

Sources of knowledge and opportunities for counselling: Ms B. has learned about dementia from reading, from watching television and from her husband himself (by knowing him for a long time and also by trial and error).

Day structure: Days start early, with Ms B. taking care of the body hygiene of Mr B. (5.30 AM). Ms B. also prepares something to eat for Ms B. (generally, some fruits on a small plate – served around 6 AM); After changing his clothes, he goes back to sleep and wakes around 9 AM for breakfast, when a more consistent meal is prepared for him by his wife (e.g. tea, bread and some cheese). He then spends the morning watching TV for a few hours, followed for a short nap before lunchtime. This time interval is used by Ms B. to shop for groceries and run errands. Lunch time is between 13.00-14.30 and the lunch consists of one course meal. After lunch Mr. B. watches sport on TV (both Ms And Mr. B. have practiced several sports during their lifetime. Ms B. is still occasionally playing tennis). Sometimes, he and Ms B. discussed a game or match (they particularly like watching tennis games). During the day, sliced fruits or other healthy snacks are prepared by Ms B. for her husband. Dinner also consists of light meals (fruits, salads) as Mr. B. suffers from diabetes and Ms B. tries to keep his weight under control (because he is also not able to move too much).

Challenges for caregiver: Ms B. is the only caregiver of her husband (Mr. B. does not accept anybody else as caregiver, becoming violent if a stranger is imposed to him), which has a high level of dependency and requires a high level of care. This leads to a high level of burden experienced by Ms B. who says it is difficult to find time for herself. Providing physical care, episodes of violence, the self-imposed social isolation and the need to be available 24/7 for her husband are perceived as the most troubling aspects of caregiving.

2.5.4 OBSERVATION 5: INFORMAL CAREGIVER'S HOME IN RUMANIA (MR. G.)

General information of the observation session

Period of observation: 06.10.2017 – 15.11.2017

Researcher: Raluca Sfetcu

Social setting and physical environment: Ms G. is a new client of the RAS MC. She was referred to the MC around two weeks ago by her psychiatrist. She had her psychological assessment on 4th of November, and she was offered to join the cognitive stimulation group for 10 sessions. On the day of the interview, Ms G. was attending her first cognitive stimulation group at the SRA memory centre. Mr. G. accompanied her and while waiting for his wife to finish the group we conducted the entry interview. The entry interview took place in a small room (about 15 $m^{2)}$ in the Memory Centre (MC), a three-room day centre facility managed by the Romanian Alzheimer Society (RAS). The remaining observations took place at the participant's home, a three-room apartment located in the same district as the MC.

Space and the objects in the setting: Most of the observation took place in the living room (about 25 m^2), a traditionally furnished room with a couch, an armchair, bookshelves, a television set and a small coffee table. No adaptations of the space were visible. Entry in the other rooms of the apartment was limited.

Actors in the setting: Mr. G. (born 1944) and his wife Ms G. (born 1946). Ms M. has been recently diagnosed with dementia.

Interactive patterns: Mr. G. takes care of his wife, which is still in an early stage of dementia and has a high level of independence in her daily activities. Mr. G. tries to be as helpful as he can in situations where his wife encounters difficulties (finding objects, shopping for groceries, accompanying his wife to group activities organised at the MC, etc).

Non-verbal language: Mr. G. is very courteous towards his wife (e.g. helps Ms G. to put on her coat) and very positive around her, trying to make her feel as relaxed as possible. While there is no much physical contact in the presence of the observer (this might be due to a cultural norm – still present in older generations – of showing limited emotion in front of other people) the facial expressions of Mr. G. are always kind and reassuring and his tone of voice is calm.

Goals, motivations or agendas: Mr. G.'s main motivation in taking care of his wife is to continue enjoying life together for as long as possible, as they have been doing it for almost 50 years of marriage.

Emotions: Overall, the relationship is characterized by a lot of mutual respect, kindness, calmness, harmony and love.

Sources of knowledge and opportunities for counselling: Mr. G. is beginning to learn more about dementia, especially from the interaction with medical professionals from different settings (e.g. RAS, MC). He is also using the internet for specific information.

Day structure: Mr. and Ms G. are preparing their meals together and Ms G. is still involved in this activity. They serve breakfast early in the morning and then spend some time watching TV or reading. Late mornings are dedicated for grocery shopping or running errands. After their return they prepare lunch and eat together. After lunch they take some downtime, taking short naps or just resting. In the afternoon they spend their time by watching TV, doing crosswords or reading. On the weekends they visit their children or receive visits from them.

Challenges for caregiver: Mr. G. does not yet perceive the caring process as being very challenging as the changes in their program are small right now (mainly having to be more involved in the household activities such as shopping for groceries). Additionally, Mr. G. is also accompanying Ms G. to activities planned at the MC of RAS (dance therapy, cognitive stimulation groups), where he generally waits for his wife for 1.5 to 2 hours. These hours are not perceived as burdensome either, as he hopes that such activities will keep his wife in a good shape for longer periods of time.

Reflection of observer and methodology: Mr. G. and Ms G. welcomed the observer into their home and made her feel comfortable. They asked questions about the educational and professional background of the observer and also shared stories from their past with the observer.

Discussion: Ms G.'s health condition is still good: she is still involved in household activities and has a high degree of independence in self–care activities, which reduces the burden of care for her husband, at this point in time. Also, Mr. and Ms G. have managed to develop a slow paced daily routine, which gives an overall sensation of calm and harmony.

2.5.5 OBSERVATION 6: INFORMAL CAREGIVER'S HOME IN RUMANIA (MS D.V.)

General information of the observation session

Period of observation: 06.10.2017 – 15.11.2017

Researcher: Raluca Sfetcu

Social setting and physical environment: Ms D.V. (born 1938) lives with her daughter Ms D.T. (born 1968) and her daughter's partner (F.Z). in a three-bedroom house in a residential area at the periphery of Bucharest. Ms D.V. was diagnosed with AD in February 2017. Since than she lived with the sister of the participant for several months and lived alone in her home for another few months(in Oradea, a city in the north of Romania). In October 2018, she moved to Bucharest and now lives with the participant, Ms D.T.

Space and the objects in the setting: The room where Ms D.V. lives is adapted, initially being used as a reading room. The walls of the room are occupied by shelves filled with books. In the centre of the room there is a couch. The room has big windows and enough light gets in. Several apartment plants are also distributed throughout the room. The other room, where D.V. spends a considerable amount of time, is a spacious kitchen.

Actors in the setting: DT, RS

Interactive patterns: Now and then Mr. R. helps Ms A. to get more comfortable by placing a pillow under her back or by bringing her a small snack (a package of biscuits).

Verbal and non-verbal language: Ms D.T. is a very warm person and she is showing her affection through physical contact as well as through the words she uses. Interactions also show a high degree of respect and appreciation.

Goals, motivations or agendas: The relation between Ms DT and Ms DV is a very strong one. The appreciation Ms D.T. has for her mother and the strong connection they had in the past are strong drivers for providing care.

Emotions: Ms D.T. speaks very dearly about her mother. She is using diminutives and other words filled with affection (e.g. Museta). Interactions are filled with humour, difficult conversational situations are being transformed into reasons for amusement (especially when D.T., D.V. and E.Z. are together).

Sources of knowledge and opportunities for counselling: Internet, specialised medical events (learning from other participants, which are caregivers as well), her mother herself (e.g. she is telling me not to get upset because she can't do it anymore).

Day structure: Ms D.V. wakes up at 9 AM, uses the bathroom for self-care, takes medication and eats breakfast together with Ms D.T. and F.Z. Then she bicycles on the electric bike or walks around the home. She takes lunch with either D.T. or F.Z. (depending on who arrives home first). In the afternoon she joins her daughter in the kitchen where she helps Ms D.T. or does other types of activities in the presence of the daughter (e.g. talks on the phone daily with her second daughter or a friend). When alone at home, she sits in her room by herself – without watching TV or doing other types of activities. She leaves her room just for using the bathroom and is heavily dependent on her daughter for being active. Other activities she enjoys doing are shopping, having her manicure/pedicure done in a cosmetic shop (once a week), joining her daughter for a drive around the city (on weekends). She used to read and write more but now she started to find less pleasure in these activities and only rarely accepts to do it. A paid caregiver also visits sometimes and spends time with Ms D.V.

Challenges for caregiver: the main challenge for Ms D.T. is the lack of time. She feels that in order to provide proper care you need a lot of time but – as she still works fulltime – it is difficult for her not to feel often guilty. Finding pleasurable activities for her mother and finding the right balance of activity and rest (periods of 2-3 hours of activities must be broken down by short periods of rest of 30 minutes). The caring activity – even if it is for a loved one – must be approached as a work task (with a certain level of professionalism and detachment) in order to avoid the burnout of the caregiver. Stigma is also a problem, every presence in the public in the company of the PwD having the potential of becoming a frustrating experience due to the reaction of the other people.

2.5.6 IMPLICATIONS FOR THE SUCCESS APP

For informal caregivers, the app seems to be even more necessary than it is the case for professional caregivers for a number of reasons.

First, family members of dementia patients lack any formal training about the disease. They have to find a way to learn about the illness and not everyone has the same access to knowledge, depending among others, on their own age and physical fitness, but also on their socio-economic status and education. The literature on dementia that is available for lay persons still relies on the heavy use of medical vocabulary that is not easy to understand. The internet is an excellent source of knowledge, but especially spouses of persons with dementia are often digitally illiterate and unwilling to learn about these new technologies.

Second, informal caregivers fulfil a double role in the patient’s life: on the one hand, they are emotionally involved with the patients, either as spouses or children, and on the other hand, they have to fulfil a new role as caregiver. Assuming these two roles can become a source of emotional and physical stress, and therefore they are in desperate need of easy support and help.

Third, informal caregivers do not have access to the same social informal resources as professional caregivers. While all the caregivers interviewed in the day care facilities reported that they always ask their colleagues for help first when they are in need or do not know what to do, informal caregivers do not have this invaluable source of knowledge.

For these reasons, the SUCCESS app should be tailored specifically to the needs of informal caregivers. The design and structure of the app should be user-friendly and should work on all smartphones (both iOS and Android). Given the fact that the informal caregivers are often the same age as the patients and very often not very familiar with digital technologies, the app needs to be as intuitive to use as possible. Also, it would make sense for the developers of the app to print an instruction booklet and to send it via mail as a hard copy to the people who download the app or find other ways to explain the users how the app works (maybe offering free introductory courses or instruction videos on YouTube). The biggest challenge to reach its desired customers or users is not the app itself, but to make sure that the people who need the app will download it and use it. Therefore, a lot of effort has to be put into lowering the digital barriers that divide essentially non-digital customers from digital contents.

2.6 RESULTS OF ETHNOGRAPHIC OBSERVATIONS: FORMAL CAREGIVERS

2.6.1 OBSERVATION 7 DAY CARE CENTER 1 IN VIENNA

General information of the observation session

Time of observations: 4th of July, from 9 AM to 4 PM and 25th of July, from 9 AM to 4 PM

Researcher: Kaan N. Özemek

Social setting and physical environment: The observation was carried out at an adult day care center that offers various services: dementia day care (8 – 16 MMST), Alzheimer's day care, home care and 'open lunch' as an opportunity for socializing among patients. The center is run by 'CS Caritas Socialis", a Christian private foundation specialized on elderly and palliative care. It is located at the outskirts of Vienna, far from the city center, but well connected to public transport. The center has a big spacious garden and is set in a green surrounding. Its opening hours are from 8 AM to 4 PM. The center follows Dr. Cora van der Kooij's maieutics (NL), a specific pedagogically oriented care model developed for dementia patients.

Space and the objects in the setting: There were four rooms for patients in the day care center:

- 1 activity room: equipped with a circle of chairs, a big table and a flipchart for patients and caregivers to draw on. A door was leading directly to the garden.
- 1 lounge room: equipped with four chaises longues, a couple of small round marble tables with chairs gathered around a piano and a table for board games. There were a lot of pictures and photographs hanging on the walls, also of former guests.
- 2 dining rooms: in one dining room there was a kitchen unit and the dining tables were arranged facing each other to allow patients to communicate with each other during the meals. This room could fit about 15 patients. On days when the full patient capacity of the center was reached, the other dining room would be used, which was equipped with a long table.

All the rooms in which patients would spend time had glass walls so that caregivers could see what the patients were doing even if they were not in the same room with them. The lounge room was located in the middle of the center and could be observed from one activity room, from one dining room and from the hallway. The walls of all the rooms in the day care center were painted in friendly, light pastel colors.

There was also an office at the day care center to which patients had no access. The office was furnished with a desk, a computer and a round table for meetings.

Actors in the setting: The maximum capacity of the center is 27 patients, the minimum daily occupation of center at least 15 patients. On the first day of the observation, there were 18 patients at the center, on the second day there were 25 patients. The center employs five professional caregivers and one civil servant. At least 4 caregivers have to be present at the center per shift (from 8 AM to 4 PM). During the observation, five professional caregivers present at the center and one civil servant. The observer observed the work of three caregivers and interviewed them. The other two people were the center’s manager, who was working in the office taking care of administrative issues away from patients, and the other person had gone on a trip to a museum with a few patients.

The observer observed and interviewed the following caregivers:

Ms B. (51 years old)

- has 12, 5 years of experience in the care of dementia patients
- She has a university degree in pedagogy and later took formal training as a caregiver
- She takes care of patients during the meals and offers them company and the opportunity for conversation
- She gives physical activity courses and memory enhancing courses.

Ms S. (30 years old)

- Has 7 years of experience in the care of dementia patients
- Formally trained as a nurse for elderly people
- She is responsible for the preparation of meals
- She performs medical services (changing bandages, measuring blood pressure, sanitary care)

Ms N. (35 years old)

- Has 4 years of experience in the care of dementia patients
- Formally trained as a nurse (4 years)
- Administrative role (schedule planning, admission, etc.)
- Responsible for medication
- Vice-manager of the center

The observations of the day care center 1 are described together with the observations of the day care center 2 in the following chapter.

2.6.2 OBSERVATION 8: DAY CARE CENTER 2 IN VIENNA

General information of the observation session

Time of observation: 5th of September, 9 AM to 4 PM and 7th of September, 9 AM to 4 PM

Researcher: Kaan N. Özemek

Social setting and physical environment: The observation was carried out at an adult day care center that offers various services: dementia day care, Alzheimer‘s day care, home care, multiple sclerosis care and psychiatric care (depression, schizophrenia). This centre is also run by ‘CS Caritas Socialis’, a Christian private foundation specialized on elderly and palliative care. The center is located in the center of Vienna and is well-connected to public transport. The center also follows Dr. Cora van der Kooij‘s maieutics (NL), a specific pedagogically oriented care model developed for dementia patients. Patients at the day care center are divided in two groups: patients with onset (18 – 30 MMST) and patients with severe dementia (3,4 - 7 MMST).

Space and objects in the setting: There were five rooms for patients in the day care center:

- 2 big multipurpose rooms: There was one multipurpose room for each patient group. The multipurpose rooms were used for dining and social activities, they were furnished with tables, chairs and chaises lounges.
- 1 lounge room: The room was furnished with chaises lounges and a piano.
- 1 room for psychological care and medical services: In this room patients receive medical assistance, it is equipped with a stretcher, a desk and medical facilities.
- 1 craft room: The room is furnished with a big table in the middle and shelves where the craft utilities were stored (crayons, clay, scissors, paper, etc.).

There were three offices at the center to which patients had no access. One office was used as a meeting room for staff, the two other offices were occupied by the center's manager and the vice-manager.

Actors in the setting: The maximum capacity of this center is 28 patients, the minimum daily occupation of center is at least five patients. The center employs five professional caregivers and two civil servants. At least four caregivers have to be present at the center per shift.

Five caregivers were observed and interviewed. On the first day, there were 15 patients and on the second day there were 22 patients.

The observer observed and interviewed the following caregivers:

Mr. MX. (64 years old)

- has 22 years of experience in the care of dementia patients
- Formally trained as a nurse, specialized on psychiatric diseases
- Manager of the day care center
- Responsible for administration (organization, admission, etc.) and planning of the patient‘s activities
- Also responsible for taking care of patients
- Counsels patient‘s family members, doctors, pharmacists and associated organizations
- Co-founded the day care center

Ms SA. (50 years old)

- Has 23 years of experience in the care of dementia patients
- Formally trained as a nurse for elderly people
- She is responsible for the entertainment of the guests and their care
- Memory enhancing activities

Mr. MR. (37 years old)

- Has seven years of experience in the care of dementia patients
- Formally trained as a nurse
- Responsible for the meals (preparation, service), activities (games) and body care

Ms E. (57 years old)

- Has 14 years of experience in the care of dementia patients
- Formally trained as a nurse
- She is vice-manager of the center

- She is responsible for the entertainment of the guests and their care as well as for memory enhancing games
- Counsels patient‘s family members, doctors, pharmacists and associated organizations

Mr. A. (49 years old)

- Has 7 years of experience in the care of dementia patients
- Has no formal training in caregiving
- His main responsibilities are the care of patients and the documentation of their daily physical and emotional state

Interactive patterns:

Observed Communicative Patterns between caregivers and patients:

The caregivers had a highly empathic approach with patients, took very good care of them and treated them in a respectful manner. The observer noticed a very discernible communicative pattern in the behaviour of the caregivers: they would only ask patients that allow ‘yes’ or ‘no’ as an answer. They explained to him that they actively avoided other types of questions (why? what for?) because they make the patients feel accused of something or judged. In their communication with patients, caregivers are very clear and unequivocal, for example by articulating brief sentences.

If a patient loses orientation, the caregiver asks questions to help the patient realize that they have lost orientation. The caregivers might also have to temporarily adopt the patient‘s version of reality in order to ‘get the patients back’ to the present. This strategy was described as ‘validation’ by one of the observed/interviewed caregivers. If one patient has a crisis, the caregivers have to react quickly and isolate him or her from the group in order to avoid the single patient‘s crisis to affect the group dynamic. In general, caregivers treat patients in a respectful manner also in crisis situations and are advised to avoid infantilizing them or disrespecting them in any other way.

If one caregiver is overwhelmed by a patient, they can ask a colleague to take over (this is not an option for caregivers who work at patients‘ homes and therefore a big challenge for them). Also in stressful situations the caregivers must maintain calm as patients are very susceptible to the caregivers‘ emotions. Caregivers are advised to judge situations objectively without getting involved emotionally.

Observed Communicative Patterns with fellow caregivers

In presence of patients, caregivers mostly rely on eye-contact to communicate with each other. If they have to talk to each other in front of patients, they keep conversations very short. For longer conversations and counselling with colleagues, the caregivers go to the office or to a room reserved for that purpose. The flat hierarchy of the organization distributes responsibility equally among the team members - this creates a friendly and equal work environment. In case of need, the caregivers help each other out without hesitation.

Daily routine at the day care center:

- 9 AM – 10 AM: Breakfast
- 10 AM – 11 AM: Memory games and physical activity
- 12 AM – 1:30 PM: Lunch

- 1:30 – 3:30 PM: Activities in small groups (conversation, crafting, games)
- 3:30 PM: Snack
- PM: End of the day, patients are picked up and taken home

Non-verbal language: In dealing with patients with severe dementia, physical contact becomes a crucial communicative tool and a replacement for verbal exchange. The caregivers were doing their best to make the patients feel at ease and by slightly touching them on the arms or shoulders they were reassuring them.

Goals, motivations and agendas: The caregivers encourage patients to maintain and hone their hobbies and skills. The record of the patient's biographies are helpful tools for caregivers to assess these hobbies and skills. Caregivers challenge patients to preserve their cognitive and behavioural capacities, this is because the brain is seen as a muscle that needs to be trained despite the disease.

Furthermore, caregivers must entertain patients, enable contact with fellow dementia patients in order to avoid isolation, create solidarity among patients and to facilitate friendships. It is in the responsibility of the caregivers to create a safe environment for the patients in which empathy and respect allow patients to feel at ease with themselves and their disease. They are also intent on creating a positive group dynamic among patients.

Emotions: Overall, the caregivers at the day center were engaged in an intense process of emotional management. They were doing everything in their power to avoid negative emotions such as stress and anger, or at least to contain outbursts of negative emotions from single patients so that they would not 'spread' on the rest of the group. Their main goal was to create and foster positive emotions such as calm, tranquillity and cheerfulness.

Sources of knowledge and opportunities for counselling

- Caregiver's own professional training
- Continuous in-service training (40 hrs of training in 5 years are mandatory, otherwise loss of licence to practice as a professional caregiver)
- Caregiver's own professional experience acquired over the years
- The maieutic care model represents a structured knowledge base for the caregivers and offers perspectives on the disease through which they can find practical solutions to problems
- Discussion with colleagues is the main source of knowledge (enhanced by the constant documentation of patients)
- Hotline for caregivers for emergency situations

Technology as a source of knowledge at the day care centers:

- 'care center' software → indispensable for the organization and planning of the day care centres: The program contains all data relevant to the patients: biography, symptoms, diagnosis, care stage, medication, contact data (family members, doctors), medical advice, patients' preferences.
- 'memo fit' software → installed on tablets or computers used for memory enhancing training with patients. The software is based on a game approach.
- Caregivers seek information on the internet and google queries pertaining to their work if consultation with colleagues or consultation of on-site literature bears no results.

Meals at day care center 1 and 2: The meals follow the same procedure in both day care centers. The patients at the day care center eat three meals during their seven hours stay at the center. At 9 AM, breakfast is served for an hour, from 12 AM to 1:30 PM lunch is served and at 3:30 PM the patients are served a snack. In the morning, patients can choose their lunch from a menu. The meals are prepared somewhere else and delivered to the centers in food containers. The civil servants distribute the food to the patients and prepare the beverages in the kitchen units of the dining room. Two caregivers assist the patients during the meals: they help those patients who cannot eat by themselves and keep the others company. At the end of the meals, the civil servants collect all the plates and cutlery and clean the dining rooms.

Daytime activities at day care center 1: The patients met in the activity room and played memory games with one caregiver from 10 to 11 AM. In one game, the patients sat in a circle and the caregiver would partially read sayings from a book aloud to the patients asking them to finish the sayings. In another game, the caregiver mentioned a number and the patients were asked to tell her what they associated with that particular number.

Afternoon activities at day care center 2: At the day care center 2, the observer observed an activity tailored to train the motoric capacities of the patients. After lunch, two caregivers hold a board of approximately one per one meter with 4 round holes in different sizes. Each hole was given a specific number of points, the smaller the hole, the bigger the points awarded for it. Patients were asked to throw a ball into one of those holes standing from a distance of approximately two meters. This exercise trains the patient’s capacity of spatial imagination and their physical coordination.

Reflection of observer and methodology: Initially, the observer felt uncomfortable because he was immediately recognized as an ‘external factor’ in a very consolidated group setting. It was an emotional challenge for him to get used to the specific environment of a day care center for patients with dementia as he has had no prior contact with the disease. However, he was able to quickly establish a connection to the agents in the field and to overcome the status as a total outsider. It was not possible for him to operate in the background and he was involved in the field more than he had expected. Patients recognized him immediately as a stranger to their group and when asked why he was there and what he was doing, he had to find a way how to explain them his role without confusing them. These brief conversations with the patients were not always easy for him as he had to adjust to their physical and mental state. One of the challenges of this research was indeed this close contact with the disease. In general, he was treated with respect and the caregivers were very open to the research and its goals.

As for the methodology, participant observation of group dynamics such as the ones he witnessed at the day care centers poses several challenges to the researcher. There are many things going on at the same time and one has to constantly take micro-decisions as to which scene deserves one’s attention and which can be neglected. This also translates into the process of taking notes which tends to be postponed to after the observation is over so as not to miss any important scenes. Therefore, it would make a lot of sense, if two researchers would carry out the participant observation at day care centers because the size of the group cannot be managed by one researcher alone.

Discussion:

The life at the day care center is characterized by invariable routines and structures. This fixed social order is needed not only by the caregivers to manage the complex situation of being responsible for patients with a disease that, among others, impedes their mental judgment or makes them do 'irrational' things. The social order is also welcomed by the patients themselves who find comfort and a sense of security in the rhythms of the day care center. But the way in which the routines are organized at the day care centers was very much centered on the needs of the patients and on the respect for them as human beings. The maieutic care model combines pedagogical behavioral principles with strategies from traditional nursing science and it was applied in both day care centers as a paradigm of practice. The emotional sensitivity and compassion with which everyone working at the day care centers interacted with patients deeply impressed the observer. Professional caregivers are engaged in a constant process of emotional management and they have to be able to shield also their own negative emotions (stress, feeling overwhelmed) from patients. The mutual support they give each other is an invaluable resource for them, not only in terms of knowledge exchange, but also in terms of moral and psychological support. The teams at the day care centers work in perfect accordance with each other and daily meetings and discussions about the patients are part of their job. The trust and respect among the team members was perceptible and the observer thinks that all the people working at the day centers are proud of their work environment. Patients felt at ease, and so did their relatives, who knew that their loved ones are in good hands.

Overall, there is a fundamental difference between caregivers for homecare and caregivers working at day care centres. The caregivers who work at the day center are interacting with patients who are guests and know that they have to follow certain guidelines. At the same time, the caregivers are never alone with the patients and can always ask their colleagues for help. On the other hand, caregivers who work at people's homes are confronted with a completely different situation: not only are they alone with the patients and do not have the opportunity to exchange opinions with fellow caregivers, they are also the patient's 'guests' and this changes the power dynamic between patients and caregivers.

2.6.3 OBSERVATION 9: FORMAL CARE (PATIENTS HOME) IN RUMANIA (MR. B)

General information of the observation session

Period of observation: 06.10.2017 – 15.11.2017

Researcher: Raluca Sfetcu

Social setting and physical environment: Ms A. is 75 years old and was diagnosed with dementia seven years ago. She lives with a paid caregiver (Ms R.) in a 3-room-apartment in the city centre. She has two daughters: one living in Bucharest and one in Italy. The daughter living in Bucharest has a limited involvement in the care process, visiting Ms A. once a week and phoning her mother's caregiver Ms R. in the evenings. Ms R. has been taking care of Ms A. for the last 6 years.

Space and the objects in the setting: The whole flat is adapted to be suitable for a person with dementia. The rooms are only basically furnished and decluttered (e.g. in the living room there is a couch and an armchair, a TV set, a desk with a computer on it and a small coffee table).

Actors in the setting: Ms A., Ms R., R.S.

Interactive patterns: During the observation sessions Ms A. had a limited amount of contact and interaction with Ms R. Ms A. mainly watched TV and only in rare occasions initiated a conversation (this might be partly due to a recent change in medication because of restlessness during the night).

However, when addressed a question, she tried to reply. Ms R. is closely observing the behaviour of Ms A. and tries to anticipate her needs (e.g. bringing a small pillow to make her more comfortable, preparing a snack, etc).

Verbal and non-verbal language: Ms R. is using affectionate words when addressing Ms A. and is overall friendly both in voice and gestures.

Goals, motivations or agendas: Ms R. is paid for taking care of Ms A. 24/7.

Sources of knowledge and opportunities for counselling: movies, TV shows, face to face and online course for caregivers.

Day structure: The day starts with taking care of the hygiene of Ms A. Afterwards, Ms R. prepares a light breakfast for Ms A. After breakfast Ms R. dresses Ms A. and they are going out for a short walk. Walking used to be one of the favourite activities of Ms A., who used to practice several sports when she was young (gymnastics, swimming, dance). After returning they eat lunch and Ms A. gets some rest. The afternoon is spent watching TV or listening to music.

Challenges for caregiver: Night-time restlessness and wandering (e.g. leaving the flat in the middle of the night) represents one of the main care challenges. Taking care of the personal hygiene can also sometimes represent a challenge as well as occasional aggressive behaviour.

Implications for the SUCCESS app:

Feedback on the SUCCESS approach

Most participants think that there is no need for an app to support caregivers in their work because there already exists a well-functioning support system among colleagues. However, since participants gave this feedback based on their anticipation of what the application will provide, this aspect should be further evaluated in lab settings.

The formal caregivers all agreed that the app could be useful for non-professional caregivers of PwD in homecare as they do not have any support network available and often lack specific knowledge and experience with the disease. Likewise, the civil servants who work at the day care centers could be seen as a potential target group for the app. They also lack professional training and despite the fact that they work in a team with professional caregivers, they could need the app. The app should be easy to use, intuitive and easy to read if it should be actively integrated in a caregiver‘s work routine and take into account the specific needs of elderly users.

Expectations for the app

1. It should deliver basic information about dementia → not only text-based, but also visual and audiovisual material
2. It should provide information as to where to get help in emergency situations → the app should access or create networks and connect different medical, social and legal agents
3. It should be possible for the app to be used via voice command (no use of hands)

4. It should also provide emotional support for caregivers and help them to manage stressful situations through the use of motivational quotes, etc.

Generally speaking, there is no pre-determined recipe for the care of PwD. The requirements for the app pertain to delivering information, connecting stakeholders and providing individual emotional support to professional or non-professional caregivers.

Despite the fact that they take regular trainings and courses, the caregivers that were part of this study are not aware of the newest research. They rely on a model that is already more than twenty years old and that works very well for them, however they seemed reluctant to new methods and strategies, particularly if these were connected to the use of digital devices such as smart phones. Therefore, one of the main challenges for the SUCCESS app developers represents the barrier between professional caregivers and their consolidated knowledge.

3 EXPERT WORKSHOPS/INTERVIEWS

3.1 AIM OF THE EXPERT WORKSHOPS

On the basis of the participant observations and the subsequent expert workshops/interviews, our preliminary scenarios will be validated and refined to stimulate design concepts and to validate the service and interaction design.

3.2 RESEARCH QUESTIONS TO BE ANSWERED

The expert interviews should clarify the initial ideas and plans of how the SUCCESS app will be implemented. In more detail, the research questions to be answered will be:

a) Scenarios: How valid are the scenarios? Do the experts see any kind of inconsistency between the scenarios and their experience with dementia? If so, in which way?

b) Gamification: How reasonable is the proposed approach for caregivers of PwD? How much gamification should be involved?

c) Needs of users: How far do the planned contents cover all the relevant needs that caregiver of PwD have? Is there an important aspect missing that is not so far planned to be included in the app? If so, which aspects?

d) Structure of the App: How could the app be structured in a good way? Which filter options allow the user to quickly find the relevant information?

3.3 METHODS

AIT in Austria and RAS in Romania will conduct the expert workshops/interviews. According to the timely resources of the experts and as a consequence thereof the possibility to schedule a common appointment for both experts, it will be decided per study site if a workshop with both experts or two separate interviews with each are conducted.

First, the general idea of SUCCESS will be presented to the experts. Following to that, we will present the defined scenarios in form of visualizations to the participants and will further discuss them. Each scenario will be followed by some questions to evaluate, if the scenario is reasonable and if an aspect is missing (see interview guide in Appendix C).

In general, the workshops/interviews should allow to openly discuss about our plans for the SUCCESS app. Critical comments are explicitly requested.

3.3.1 MATERIAL NEEDED

- Visualisations of the scenarios
- Workshop/interview guide
- Voice recorder (Smartphone, etc.)

3.3.2 PARTICIPANTS

In the workshops/interviews we will ask dementia experts for their opinions. Dementia experts can be a) medical professionals that work closely with PwD, e.g. nurses or physicians or b) people who deal with dementia in other contexts, e.g. members of self-support groups, informal caregivers.

Altogether, 4 experts will be involved to gain feedback to the current plans of the SUCCESS solution.

3.3.3 SUPPORT FOR CAREGIVERS TO TAKE PART IN THE STUDY

In case of caregiver participation, we will clarify with each person individually, if they need someone to care for the PwD during the time of the interview. We will support the person to take part in the study by taking over the costs for the alternative care, e.g. day care center.

3.4 STUDY PROCEDURE

PROCEDURE	DURATION
EXPLAINING AIM AND METHOD OF THE STUDY	10 min
INTRODUCTION ROUND	5 min
CURRENT STATUS OF SUCCESS	5 min
PRESENTATION OF SCENARIOS, FOLLOWED BY INTERVIEWS	40 min
DISCUSSION AND BRAINSTORMING SESSION	25 min
GIVING THANKS, FAREWELL	5 min
TOTAL	**90 min**

3.4.1 INTRODUCTION ROUND

At the beginning of the workshop, the researchers will briefly introduce themselves and ask the participants to tell about their experience with dementia (see first question in Appendix C).

3.4.2 CURRENT STATUS OF SUCCESS

The researcher will present the current status of the SUCCESS project. The following aspects should be presented by the researcher:

- Definition of the target group
- Structure of the meta-model explaining the different levels, content types and kind of planned content

3.4.3 PRESENTATION OF SCENARIOS, FOLLOWED BY INTERVIEWS

The SUCCESS scenarios will be presented to the experts in form of storytelling supported by visualizations (see D2.2).

Each scenario presentation is followed by some interview questions. A semi-structured interview should allow the researcher to cover all relevant aspects but also to keep the interview open for discussions and to follow the participant’s comments with additional questions, which are not part of the interview guide. The interview guide is described in Appendix C.

3.4.4 DISCUSSION AND BRAINSTORMING SESSION

In a brainstorming session, the researchers will further discuss about the structure of the app and the presentation of information. This part will try to answer three main questions:

a) How should the application be structured?

To answer the first question, we will present the proposed structure (see Figure 2), which is based on the SUCCESS meta-model (see Figure 1), and evaluate it with the experts to see if and how the structure of the app could be adapted.

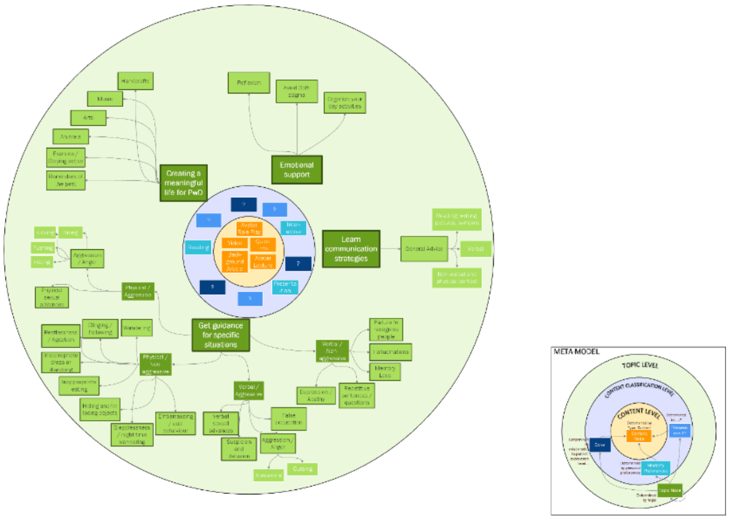

Figure 1: SUCCESS Meta-Model

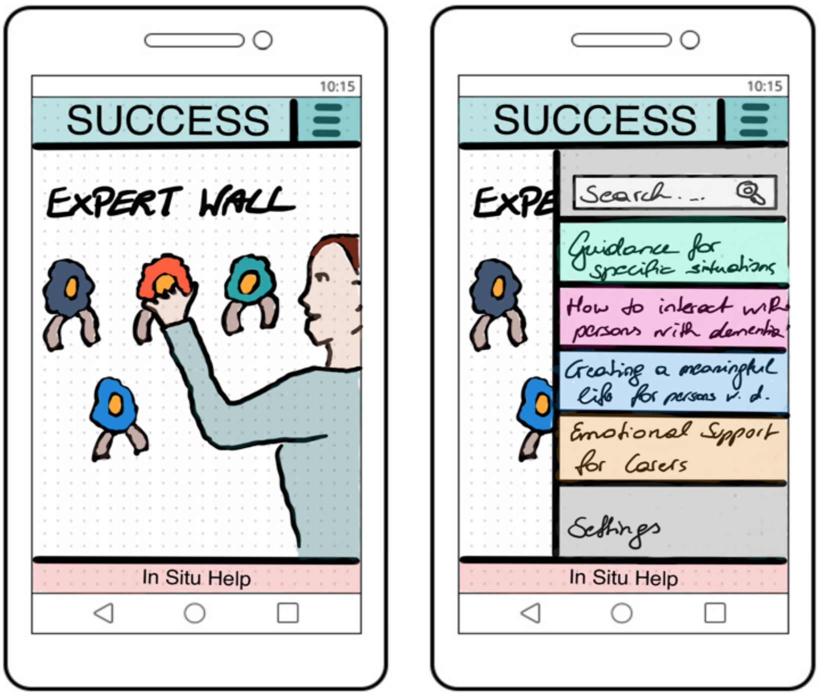

Figure 2: First draft of the interface design
(left picture: home screen, right picture: menu navigation after tapping the top right button)

b) What is the best way to allow the user to efficiently find the information that he/she needs?

The final app will offer extensive information, leading to long lists of e.g. specific situations or meaningful activities. To avoid a lot of scrolling until the user finds the desired information, the application needs well-conceived search functionalities or filter options (see first draft of the interface design in Figure 3). Together with experts, we will try to identify appropriate and meaningful filter categories to get to the specific content that the user is searching for. The discussion about filter categories will be based on the outcomes of question a) How should the application be structured?

Figure 3: First draft of interface design - Filter options in submenu 'Get guidance for specific situations'

c) How can the role-plays be designed to avoid stigmatizing the people with dementia?

During role-plays, the SUCCESS app will present different reactions of PwD, ranging from screaming to repetitive movements. It is of special interest for the project to, on the one side, show how PwD may react to a situation to allow users to learn about it without, on the other side, stigmatizing the PwD. Together with the experts, we will discuss ways to find a viable way in representing PwD in role-plays. The presentations must not be derogatory, exaggerated and stereotypical. To find the balance, experts are asked for pitfalls and positive examples.

3.4.5 DATA ANALYSIS

The outcomes of the workshops will be analysed by the partners in Romania (RAS) and Austria (AIT). The feedback of participants will be clustered according to upcoming themes and summarized in a written report. The outcomes of both workshops will be discussed among the consortium partners to clarify needed updates on the interface design as well as on the scenarios, the final structure of the app and the filter options. New ideas for the SUCCESS app that possibly come up during the workshops will be discussed in the consortium to clarify their integration within the app.

3.5 RESULTS OF THE EXPERT WORKSHOP

3.5.1 EXPERT WORKSHOP IN AUSTRIA

On 12 September 2017, AIT welcomed two experts in the field of dementia to discuss and evaluate the current plans of the SUCCESS project. The workshop was held by two project partners of AIT in AIT's focus lab in Vienna. After a brief introduction about the aim of the SUCCESS project, the informed consent forms were handed out to the two experts and signed by them. Thereafter, the researchers gave a detailed presentation about the target group and the kind of intended output of the project. To get to know each other, both the researchers and the experts introduced themselves. The experts were asked to briefly describe their points of contact with the disease dementia. Three

SUCCESS scenarios were then presented to the experts. After each scenario, the researchers asked some questions to discuss about validity of the scenario and the usefulness of the presented SUCCESS feature. The last part of the workshop covered the discussion about how to structure the app to support a quick navigation through the app.

Participants

Both experts were female and between 55 and 65 years old. Ms G. works as a social counselor and, since several years, she cares for her parents who both live with dementia. She took several courses in Austria to learn about the disease and how to support persons with dementia. Her main aim for taking those courses was to keep a loving relationship to her parents. The other expert, Ms M., has a leading position in the Austrian association for caring relatives, thus has a lot of interaction with informal caregivers. Ms M. is part of the coordinating team of the dementia strategy, which forms a framework of participatory and consensual goals, the achievement of which improves the living conditions of people with dementia. She also guides the so-called dementia-friendly districts in Vienna and has a political position in the Austrian government.

Scenario 3 - Creating a meaningful life for PwD – suggestion and information

After presenting Scenario 3, which gives an impression of how the part ‘Creating a meaningful life for PwD’ will be implemented, the following aspects were highlighted by the experts:

- In the experts’ view, it would be important to **suggest the activities based on the stage of dementia**, otherwise the spectrum of activities would be far too broad and there is a big chance that the suggested activity is not suitable for the PwD. Therefore, the app should somehow **evaluate the stage of dementia** and prompt to indicate updates of the severity on a regular basis.
- The experts wished that the app would **suggest activities based on the PwD’s biography**. For example, if the person was a boxer, it could suggest to bring some boxing gloves and to play a boxing fight to see if the memories of the part re-emerge.

Scenario 4 - Emotional support

The following feedback was given by experts:

- If someone doesn’t want to speak about the own feelings, the person would may do that with an avatar.
- It is important that the app really manages to make the user reflect his/her own situation.
- Within this app feature, the experts see two things to be essential to achieve:

  1. Mindfulness towards oneself: it is important to build in a lot of reinforcement => to strengthen the self-esteem

  2. Allowing oneself to ask for help and to get help
- However, the experts think that the practical tips (scenario 3) are already very useful

- Speech input is perceived as important for the interaction with the avatar. The experts think it can be better appreciated by the user when the avatar says "it is totally okay (to have these feelings)" than when it is presented on the display, especially for someone who doesn't like to talk about the own feelings.
- The experts perceived the scenario as unrealistic: “A man who has never cared about the household can only do this with the help of his neighbor? I don't think so, because he is already fully stretched with the relationship situation. He would realistically need external support for the household.”

Scenario 5 – Gamification

The following feedback was given by experts:

- The role change aspect is good to increase caregiver’s self-esteem.
- Gamification within the app was appreciated as a relaxing component: “I would appreciate it very much.”
- The experts also thought that gamification allows a low threshold to start using the app.
- The experts appreciated the option to have the situations presented in different rooms of the house in the birds-eye perspective.
- It was important for the experts to not provide negative feedback to the caregivers.

General comments

In general, the experts doubt if formal caregivers would like to use the app as they may think that they already know most of the information that the SUCCESS app would provide. In this case it is important to generate the acceptance to try it out. Therefore, the experts stress that the app must be **easy to use even for older persons** and that the app must **consider the potentially very stressful situation** in which the caregiver currently is.

When asking the experts what to consider to increase caregivers’ acceptance towards the app, they suggested to reduce the caregivers’ effort for installing the app to a minimum. Ideally, they should have the option to go to a **shop where the employee installs the app for them**. Otherwise, the **case manager who visits the PwD** on a regular basis could support in this. They also suggested to have the SUCCESS app **preinstalled on a senior smartphone**. Another idea would be to integrate the app in **training courses for caregivers** provided by associations or to suggest the app to relatives during the **hospital discharge management**. One expert think that the district administrations would have interest to present the app in course of the dementia-friendly district. For the formal caregivers, experts think that there would be a multiplier effect: If a formal nurse sees the benefit/benefits from this, he/she will recommend the solution to others. It can also be a relief for informal caregivers.

Further, the experts think an **introduction tutorial** would help to get used to the app.

The experts suggested to use **speech control** to filter the content that the user needs. However, the speech control should work on a solid basis otherwise it would even exaggerate the stress level of the user. Complemented by a touch interaction, this issue could be reduced.

One expert thinks a real person would be better than the avatar. However, when using an avatar, then the **avatar should look at the caregiver** to make the caregiver feel as if he/she is talking to a person.

Search strategies and filter options

- The experts wish to have voice control (see above).

Discussion on possible filter options:

- The experts suggest to ask if the caregiver is having an "emotional problem", a "practical problem", etc.
- The filter options "(non-)aggressive" or "(non-)verbal" are perceived as probably too complex by the experts.
- The experts would suggest to list the situations according to their importance (most frequently searched situations/support).
- However, the experts also very much appreciated the graphic representation (rooms) as good alternative.

3.5.2 EXPERT INTERVIEWS IN ROMANIA

Participants: Two experts were individually interviewed. Both experts were female and between 55 and 65 years old. Ms D.T. works as a family doctor and recently she started caring for her mother who lives with dementia. The other expert, Ms E.D., is working as a social worker and activities manager at the Memory Center run by the Romanian Alzheimer Society (RAS). She is involved both in the therapeutic activities as well as in other projects implemented by RAS.

Scenario 3 - Creating a meaningful life for PwD – suggestion and information

After presenting Scenario 3, which gives an impression of how the part 'Creating a meaningful life for PwD' will be implemented, the following aspects were highlighted by the experts:

- To include information on the importance of **balancing the benefits of certain activities with the pleasure** the PwD gets from doing something (e.g. eating sweets is not healthy, especially if the PwD suffers from other physical disorders such as diabetes; however, eating sweets might bring pleasure in the life of the PwD, which is also important).
- The experts wished that the app would **suggest how to motivate the PwD for getting involved in activities.** For example, by taking into account that the PwD might need more

time than others to get prepared and that if you attempt to rush them into an activity they might become aggressive or become inactive.

Scenario 4 - Emotional support

The following feedback was given by experts:

- More info on how to organise / re-organise your life might be helpful (you get many new tasks after you start caring for the PwD and getting support with being organised might help)
- Offer support for how to adjust in the other relations the caregiver has (e.g. the life partner for a child of a PwD, the children and other members of the family for a partner of a PwD)

Scenario 5 – Gamification

The following feedback was given by experts:

- Elements of gamification should include a way to compare with others. One example could be calculating average scores (either a general one or several specific ones) that should give the user the possibility to see how he is doing in comparison with other users.

General Comments:

- The app is useful because it helps the caregiver identify pleasurable activities for different stages of the disease. Furthermore, the app could help the caregiver plan each day in advance and balance between a number of pleasurable activities as well as finding time for the caregiver himself.

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APPENDIX A OBSERVATION PROTOCOL

Title of study			
Date of observation			
Name of observer			
Beginning time of observation		Ending time of observation	

The social setting/ The physical environment	
Space and the Objects in the Setting.	

Title of scene: Time of scene:

Title of scene: Time of scene:

Reflexion on social role of the observer:

Reflexion on methodology:

APPENDIX B INTERVIEW GUIDES FOR ETHNOGRAPHIC STUDY

B.1. ICE-BREAKING INTERVIEW

- First of all, I would like to ask you how long you've already been caring for a person with dementia?
- How did you get in the role of caring for a person with dementia?
- How are you related to the person with dementia?
- Could you please briefly describe your role and main tasks as a caregiver for people/a person with dementia?
- Is there something I should know or consider as being part of your everyday life for the next two days?
- Could you please describe the stage of dementia of the person(s) you care for? (MMSE score if known by caregiver)

B.2. POST-INTERVIEW

- (In your opinion, what are the most challenging situations in care of people with dementia? Why?)
- Where did you get your knowledge and information to care for a person with dementia?
    - Did you complete specific training? Why (not)?
- If you have a specific dementia-related question or a difficult situation in caring, how do you proceed?
    - Where do you get the information?
    - Which positive and negative aspects do these strategies have?
- I imagine that there are situations that are overwhelming and stressful. What do you do or what would you recommend others in those situations?
- If you think about technological support for care activities, what comes to your mind? Do you know any examples?
- Do you use any technological support for your care activities? If yes, which?

Presenting the idea of the SUCCESS application

- What do you think about such an application for caregivers of people with dementia?
- When you think about your daily routines, in which situations would you use such an application?
- Which requirements of the application must be fulfilled to allow the usage during care activities (during the shift)?

Participant name	
Age	

Gender	○ male	○ female	○ rather not say
Job role	○ formal caregiver	○ informal caregiver	
City of residence			

APPENDIX C INTERVIEW GUIDE FOR EXPERT WORKSHOP/INTERVIEW

Introduction of experts:

- Please give us a brief overview of how you got involved in the topic of dementia, your experience with the disease and in what way you are currently involved with the topic dementia.

After scenario 2 - Get guidance for specific situation – in situ and training:

- What is your first impression of this scenario?
- How do you think caregivers and the persons with dementia they care for could benefit from this functionality?
- Which aspects of this scenario do you find more important and which less important? Please explain why?
- Is there anything that should be changed? Why and if so, in which way?
- Do you see any missing aspects for guiding caregivers in difficult situations in care for the person they care for? If so, which aspects?

After scenario 3 - Creating a meaningful life for PwD – suggestion and information:

- What is your first impression of this scenario?
- How do you think caregivers and the persons with dementia they care for could benefit from this functionality?
- Which aspects of this scenario do you find more important and which less important? Please explain why.
- Is there anything that should be changed? If so, in which way?
- Do you see any missing aspects for guiding caregivers how to provide meaningful activities for the person they care for? If so, which aspects?

After scenario 4 - Emotional support:

- What is your first impression of this scenario?
- How do you think caregivers of persons with dementia could benefit from this functionality?
- Which aspects of this scenario do you find more important and which less important? Please explain why.
- Is there anything that should be changed? If so, in which way?
- Do you see any missing aspects for guiding caregivers how to find emotional balance in caregiving activities and his/her own needs? If so, which aspects?

After scenario 5 – Gamification:

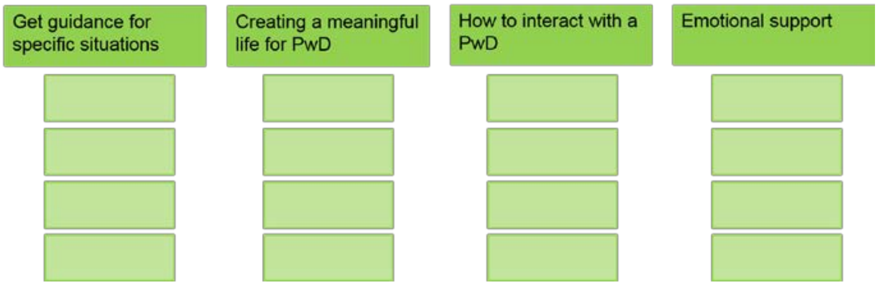
- What is your first impression of this scenario?
- What do you think about the described gameful interaction within the app?
- How do you think caregivers of persons with dementia could benefit from this functionality?
- Which aspects of this scenario do you find more important and which less important?
- Is there anything that should be changed? If so, in which way?
- Do you have further ideas for gameful approaches in the app to make the usage more interesting and fun? If so, which?

General questions:

- What is your overall impression of the system?
- Which are the best parts? Please give me 2-3 positive aspects.
- Which were the worst parts? Please give me 2-3 negative aspects.
- How would you redesign it? What would you change?
- Which needs are important and are not addressed by the system?
- What kind of functionalities would you add?
- Which needs of caregivers of people with dementia could be potentially addressed with the SUCCESS app?

Discussion and Brainstorming session

a) Structure of the app:



- Please have a look at the SUCCESS structure. The big green boxes present the main content parts of the App. Please think about the content of the different categories. Could you define subcategories?
- How reasonable is the menu? Do you think the app should be structured differently? If so, how?
- Apps can be customized to users based on their roles, actions or any other parameter of the user. Do you think the provided content has to be customized to different caregivers? If so, which categories do you think of?

b) Search strategies and Filter options:

- The final app will offer extensive information, leading to long lists of e.g. specific situations or meaningful activities. To avoid a lot of scrolling until the user finds the searched information, the application needs well-conceived search functionalities or filter options. Please have a look at the first draft of the interface design showing a search box and also the option to select filters to find the content. What do you think of this option? Can you think of another idea to let the users get the searched content?

- Please think of an example. Imagine you are a SUCCESS user and you are looking for guidance for a specific situation. What situation could that be? […] Great, let’s say you are looking for information for [the mentioned situation] and you touch the search button. Which word or words would you try first? And if that would not work out as expected which ones would you try next?
- After selecting the category “Get guidance for specific situations”, which categories should the filter option present to get the content the user searches for?
- After selecting the category “How to interact with a PwD”, which categories should the filter option present to get the content the user searches for?
- After selecting the category “Creating a meaningful life for PwD”, which categories should the filter option present to get the content the user searches for?
- After selecting the category “Emotional support (for caregivers)”, which categories should the filter option present to get the content the user searches for?

c) Avoiding stigmatizing:

- Within SUCCESS, it is of special importance for us to avoid stigma when portraying PwD. In your experience, what are the most common and/or most harmful stereotypes we should be aware of?
- Within SUCCESS and the role play training, are there stigmatizing stereotypes of special risk?
- We know that PwD are very diverse. Of course, it is always a challenge to portray diverse groups. Do you know any best practice examples? If yes, what is excellent about it? Which requirements do you think a best practice example has to meet?
- To meet diversity and dignity of PwD, which criteria do we have to keep in mind?