

#### AAL Programme

**SUCCESS** - **SU**ccessful **C**aregiver **C**ommunication and **E**veryday **S**ituation **S**upport in dementia care



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# KEY INFORMATION FROM 'DESCRIPTION OF WORK'

DELIVERABLE DESCRIPTION This deliverable describes the three evaluation phases that aim at enabling an

iterative optimization and encompasses a lab study with a low-fidelity prototype and a lab study with a high-fidelity prototype. End uses from Austria and Roma-

nia will be involved.

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# **ABBREVIATIONS**

ABBREVIATIONS	DESCRIPTION
AAL	Active and Assisted Living
AAL CMU	AAL Central Management Unit
PwD	Partici pants 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.

# 1 ABOUT THIS DOCUMENT

# 1.1 ROLE OF THE DELIVERABLE

This deliverable describes the methodological approach and results of the Iterative evaluation and user experience optimization, which is constituted of three main phases:

- 1) A low fidelity prototype evaluation (user study in the laboratory) that aimed at validating the service and interaction design concept as well as the use cases.
- 2) A high-fidelity prototype evaluation in a laboratory setting. The final evaluation included 20 representatives of the primary user group in Austria and Romania.

# 1.2 RELATIONSHIP TO OTHER SUCCESS DELIVERABLES

The deliverable is related to the following SUCCESS deliverables:

DELIVERABLE	RELATION
D2.2	Deliverable 2.2 presents the uses cases, scenarios, and services as well as the interaction design concept. D2.3 describes the methodological approach and results of the iterative evaluation of the low and high-fidelity prototypes, which are developed based on the developed use cases and scenarios.

# 2 FIRST USER STUDIES IN THE LABORATORY

In order to evaluate the first prototypes that have been developed based on scenarios and use cases, a user study in the laboratory is carried out, including overall 12 potential end users (formal as well as informal care givers).

# 2.1 GOAL AND RESERACH QUESTION

The overall goal of the user studies in the laboratory is to evaluate the first mock-ups that have been developed based on the scenarios and use cases (see also D2.2). We aim at identifying usability, user acceptance as well as accessibility problems while potential end users carry out some predefined tasks. Moreover, we aim at investigating to what extent users are motivated by the gamification elements the app provides. Based on this, suggestions for improvements are elaborated and communicated to the technical partners in the project.

#### 2.2 METHODOLOGICAL APPROACH

There are a variety of inspection methods available that allow to evaluate the usability of first prototypes, e.g., heuristic evaluations, cognitive walkthroughs, or formal usability inspections (Nielsen 1994, Holzinger 2005). A study in the laboratory is a valuable approach to perform usability testing, with mobile applications (Zhang, Adipat 2009), which pose a variety of challenges, e.g., the mobile context, connectivity, or the small screen size. We will apply think aloud (see for example Holzinger 2005) to gather information about participants' intentions/thoughts while performing a certain task. Moreover, the following user experience and user acceptance factors will be considered during the evaluation:

- **Effectiveness**<sup>1</sup> (How accurate and complete can users perform a certain task? task completion successful/not successful/with help)
- Efficiency<sup>2</sup> (task completion time, learning time)
- **Subjective Satisfaction**<sup>3</sup> (How pleasant do users experience the usage of the system? What are likes/dislikes?)
- Ease of use<sup>4</sup> (How easily could users carry out/complete a certain task? subjective experiences)
- Perceived Usefulness <sup>5</sup>(To what extent do users believe that the application would enhance their performance)

<sup>&</sup>lt;sup>1</sup> Effectiveness is the "accuracy and completeness with which users achieve specified goals". ISO 9241-11 (1998)

<sup>&</sup>lt;sup>2</sup> Efficiency is the relation between the accuracy and completeness with which users achieve certain goals and the resources expended in achieving them. Indicators include task completion time and learning time ISO 9241-11 (1998)

<sup>&</sup>lt;sup>3</sup> The three basic components of satisfaction are expectations, desires and perceived performance (Lowry et al. 2006)

<sup>&</sup>lt;sup>4</sup> Ease of use describes the degree to which an individual believes that using a system would be free of physical and mental effort (Chuttur 2009) – for the operationalization see also Davis 1998

<sup>&</sup>lt;sup>5</sup> Perceived usefulness is the degree to which an individual believes that using a system would enhance his/her job performance (Chuttur 2009)

• Accessibility (Does the target group identify any accessibility problems? E.g., Do they experience any difficulties with regard to font size)

#### 2.3 STUDY SETUP

In order to answer our central research questions, we chose to apply and experimental design that allows us to explore users' behavior in a controlled environment. Users will carry out five predefined tasks. In the following paragraph, the overall procedure is briefly described.

In the run-up phase to the study, participants will receive information about the overall project idea and the procedure of the study (place, duration, etc.). An information sheet will be handed out in advance by EURAG, who takes care of the recruitment of formal as well as informal care givers (e.g., family members). Six formal and six informal care givers will be recruited. The following selection criteria are considered: participants do have approx. one year of experience in caring for people with dementia, participants are smart phone users (preferable Android). In order to allow a participatory design process, participants in Austria will be asked if they are willing to take part in a second evaluation with the iterated prototype.

#### 2.3.1 INTRODUCTION TO THE STUDY

When participants arrive, they will be briefly introduced to the study (overall information, procedure and methodology (think aloud). Open questions (if there are any) are clarified. Moreover, participants are asked to fill out a brief questionnaire, assessing basic demographic data (age, gender, highest education, ...) and mobile phone usage (android, iOS).

#### 2.3.2 PRE-INTERVIEW

Before starting with the task, the test leader will gather information about participants' experiences with people with dementia (guideline-based interview). The following information will be assessed:

- Experience in the field of dementia care: E.g., How long have participants been working in the field of dementia care/taking care of a family member?
- Experiences when caring for people with dementia (positive and negative): What are highlights or lowlights when caring for people with dementia (personal experiences)?
- **Support**: Do participants obtain support (practical, emotional, ...)?
- **Expectations.** Do they have any expectations towards the app in terms of functionalities; if yes, what are their expectations?

#### 2.3.3 TASKS

After the pre-interview, the test leader will hand out the smart phone and will introduce the participant to the tasks (task by task). The participant will be reminded to talk about his/her thoughts while carrying out the task. Participants will receive task cards which include all relevant information to carry out the task. During the tasks, the test leader will take notes; after each task the participants will be asked to answer a few questions (e.g., how easy s/he could carry out the tasks, if problems occurred and why, if they have any suggestions for improvement). Each task is based on a small scenario to support the participants imagining a certain situation. Thereby we consider both target groups (formal and informal care givers). In the following, the tasks are briefly described.

# Task 1: Get guidance for a specific situation – training for a specific situation (based on use case 3)

**Scenario** (formal care giver): The last few months you have been taking care of an older lady with dementia. Although you have knowledge and experience with dementia you sometimes feel over challenged, because the lady often over-reacts to minor things and starts hitting and cursing. Moreover, you are often not sure how you should behave in terms of memory loss. The app provides guidance how you can deal with such situations.

**Scenario** (informal care giver): A few months ago, your mother was diagnosed with dementia. Although you have knowledge and experience with dementia you sometimes feel overcharged, because she often over-reacts on minor things and starts hitting and cursing. Moreover, you are often not sure how you should behave in terms of memory loss. The app provides guidance how you can deal with such situations.

#### Task:

- → Please search for *respectively two suggestions* on how you could cope with somebody, who starts *hitting* and *cursing* and find tips in terms of *memory loss*.
- → Afterwards, return to the home screen

#### **Questions:**

- → How easily could you find the required information? / Did you miss information? (explicitly ask participants how they experienced the navigation structure)
- → To what extent is the information useful for you? (ask why / why not)
- → Do you have any suggestions for improvement?

# Task 2: Guidance for specific situation – in situ guidance (based on use case 2)

**Scenario 2a (formal care giver)**: You just arrived at your client's home. The lady is upset and insists to go shopping. You do not have that much time this day. You start explaining that this won't be possible this day and while you are talking the lady becomes starts cursing and hitting at you. You feel slightly overstrained in this situation and decide to search for a quick advice via the app.

**Scenario 2a (informal care giver)**: You just arrived at your mother's home. She is upset and insists to go shopping. You do not have that much time this day. You start explaining that this won't be possible this day and while you are talking, your mother starts cursing and hitting at you. You feel slightly overstrained in this situation and decide to search for a quick advice via the app.

#### Task 2a:

- → Look up some *quick advice for cursing and hitting* (the first advice that is provided is not useful for you but can make use of the second quick advice).
- → Afterwards you will be automatically redirected to the home screen

**Scenario 2b (formal and informal care giver):** After you are at home again you open your app. You receive some follow-up information regarding the in-situ advice you received that day.

# Task 2b:

→ Please *rate the usefulness of the advice* (very useful) and find out how many experience points you earned this day.

→ Afterwards return to the home screen

### Questions:

- → How easily could you find the required situation?
- → Could you find out how many experience points you received?
- → What are your thoughts towards the visualization of the quick info was it useful? (if yes/no why was it useful/not useful?)
- → Can you imagine using this functionality in a case where you would need quick advice?
- → Do you have any suggestion for improvement?

## Task 3: Train your communication strategies (based on use case 4):

**Scenario (formal and informal care giver):** The app does not only provide information about possible behavior in specific situations but allows you to train and expand your skills. You have already read some useful information about cursing and hitting, so the app unlocks a training challenge for you. You are curious and since you would like to strengthen your knowledge, you decide to accept the challenge.

#### Task:

- → Please strengthen your communication skills.
- → Afterwards return to the home screen

#### **Questions:**

- → How easily could you find the required information?
- → How useful did you experience the "dialogue" with the avatar?
- → Can you imagine training you skills in a virtual dialogue with an avatar?
- → Do you have any suggestions for improvement?

# Task 4: Tips for meaningful activities / gamification (based on use case 5)

**Scenario (formal and informal care giver):** Offering activities to people with dementia can help to create meaning in their lives. Imagine that you want to provide such activities to the person you are caring for.

#### Task:

- → Explore the app for suitable suggestions for reminders of the past
- → Read more about one concrete activity you could carry out (reminders of the past)

#### **Questions:**

→ How easily could you find the required information?

- → How helpful / useful were the suggestions?
- → Would you use such a function in your day-to-day care routine?
- → What do you think about the reward provided by the app? (Do you consider the reward to be motivating?)
- → Do you have any suggestion for improvement?

# Task 5 Emotional Support / Gamification (based on use case 7)

**Scenario (formal and informal care giver):** Imagine you've had a hard day. During care, you faced some incriminating situations. You wish for a possibility to reflect upon your feelings to take care of yourself.

#### Task:

- → Explore, in what way the app provides support for reflection (after the user has found the area for self-reflection indicate that s/he should find out more about "rejuvenation")
- → Return to the home screen

## **Questions:**

- → Was the information easy to find?
- → Do you think a self-assessment (or similar wording) like in the app can support you in a comparable, real situation?
- → Would you do something different? If so, what would you change?

# 2.3.4 POST INTERVIEW/DEBRIEFING

After the participants have completed the tasks a brief guided interview takes place. The test leader will clarify open issues and will ask the participants to indicate their overall satisfaction (e.g., likes, dislikes) towards the system. Suggestion for improvement are further elaborated.

# 2.4 ORGANIZATION

# 2.4.1 RECRUITING PROFILE

Overall six formal and six informal care givers are recruited. The following selection criteria are considered:

- At least one year of experience in caring for people with dementia
- Smart phone usage (preferred android users)

#### 2.4.2 TIMELINE AND RESPONSIBILITIES

Table 1: Time and responsibilities 1<sup>st</sup> user study in the laboratory

Calendar week	Activity	Responsibility
KW45 (6.11-10.11)	Concept development, definition of tasks	AIT, TE
KW46 (13.11-17.11)	Implementation, modification of mock-ups – Translation	AIT, Center for Health and Bioresources
	Start recruitment of participants	EURAG
KW47 (20.11-24.11)	Prepare materials, pretest	AIT, TE
KW48 (27.11-01.12)	Prepare materials, pretest	AIT, TE
KW49 (04.12-7.12)	Implementation lab studies	AIT, TE
KW50 (11.12-15.12)	Implementation (back up), analysis and report	AIT, TE
KW51 (18.12-22.12)	Analysis and report	AIT, TE

#### 2.5 RESULTS

In the following the main results as well as suggestions for improvement are provided. Thereby, we will answer the main research questions, i.e., 1) How accurate, complete and efficient could users perform a certain task? 2) How pleasant do users experience the usage of the system (likes, dislikes)? 3) How easily could users carry out and complete a certain task? 4) To what extent do users believe that the application would enhance their performance (usefulness)? and 5) Does the target group identify any accessibility problems?

#### 2.5.1 PARTICIPANTS

Overall 14 participants took part in the evaluation, 7 formal care givers and 7 informal care givers. The evaluation took part in nine sessions, four sessions were carried out with one participant and five sessions with two participants at once. Almost half of them were male (n=6) and more than half were female (n=8). Participants were between 23 and 71 years old (M=53,4, SD=13,2). On average, they had 9,9 years of experience in caring for persons with dementia, whereby there were differences between formal and informal care givers. The formal care givers had between one and 28 years of experience (M=13,4, SD=9,9) and the informal care givers had between one and 15 years of experience (M=6,4, SD=4,0).

All of the participants had a smart phone and the majority of them (11) indicated that they had good or very good smart phone skills; only two participants indicated that they had bad skills and one participants did not specify any information. Six participants said that they were using their smart phone more than three hours a day, six participants between one and two hours and only two participants indicated that they were using their smart phone less than one hour a day.

#### 2.5.2 EFFECTIVENESS AND EFFICIENCY

## Task 1: Get guidance for specific situation

In terms of task 1 most of the participant had difficulties to accomplish the task accurately and efficiently. In four of nine sessions participants explicitly needed help from the test leader to solve the task. The main problems that were identified refer to **information architecture (navigation)**. Thereby the following issues were identified:

- Find the appropriate "main category" on the home screen. Within two sessions, participants were not aware that they could search for advice in "get guidance for specific situations". Alternative categories that were selected were "learn communication strategies" or "emotional support". This indicates that the main categories need to be more meaningful to support users to find guidance for specific situations.
- Find the appropriate "sub-categories". Participants were asked to find guidance in terms of hitting, cursing and memory loss. The study shows that in six out of nine sessions, participants could hardly find advice in terms of "memory loss". Here the main problem was that participant did not comprehend that memory loss could be a sub-category of physical aggressive/non-aggressive, verbal aggressive/non-aggressive. For example, one participant pointed out: "This is neither verbal aggressive/non-aggressive nor physical aggressive/non-aggressive." (Session 9). Moreover, physical sexual advances were not considered as subcategory of "physical aggressive". Particularly, the professional carers pointed out that it might be difficult for informal carers (laymen), who do not have any knowledge about different forms of behaviour, to find the right sub-categories.
- Too much navigation levels. Almost all participants indicated that the navigation structure was too complicated (too much levels), which is illustrated in the following statements: "It's tedious! This is too much mental effort!" (Session 1) "This is not logical. I could only guess where to find the solution." (Session 3) "It's not comprehensible. I would first need some time to play around with the system to know how it works" (Session 4) "This is too much. [referring to the buttons] It is irritating that I need to push that much buttons." (Session 7).
- Difficulties to recognize the globes as buttons. Finally, participants had difficulties to recognize that they could push the globes to retrieve results, i.e., the forms were not recognized as buttons.

Suggestions for improvement. In order to simplify the navigation participants suggested to reduce the navigation levels (e.g., remove the first and second level) and only provide the information on a "behavioral level" (e.g., directly search for information about hitting, cursing, memory loss). Moreover, they suggested to allow multiple choice, to easily retrieve results, e.g., if a person is hitting and cursing at somebody. Furthermore, the study revealed a variety of suggestions to improve the visual design. Participants recommended to reduce the size of the pictures in favor of huge text and clear labelling (in German not in English). In this context, all participants pointed out that the font size needs to be increased. Moreover, clear back buttons (participants had difficulties to recognize the white arrow as back button) should be implemented to allow an easy navigation back and forth.

## Task 2: Quick help

Similar as in task 1, most of the participant had difficulties to accomplish the task accurately and efficiently. Again, the most issues that were identified concern the **overall information architecture** and the **visual design**. It was not comprehensible for participants to retrieve quick help via the search field, i.e., the virtual object of the text field did not fit users' mental model to quickly receive help. Moreover, the visual design (light grey font) made it hard for participants to find the function. Within six sessions, participants needed support from the test leader to find the required functionality. Within three sessions participants were searching for quick help via "training communication strategies".

**Suggestions for improvement.** It was suggested to design a kind of quick help button that is more prominent (e.g., red button) and to automatically suggest categories or terms that could be selected. Particularly in a situation where a user is stressed (e.g., because the patient is hitting or cursing) some participants had concerns that they would be able to quickly find good suggestions via the search field. One participant suggested that it would be good if the system could automatically recognize certain behavior. Based on these appropriate suggestions could be provided.

# Task 4: Meaningful activities

Most of the participants could easily and quickly complete the task, however some of them pointed out that the structure was ambiguous and not logical, which is illustrated in the following statements: "Memories of the past could also be something related to the work of a person with dementia. In this case I would search for the information in the category work". (Session 3). "The categorization of suggestions for activities is not clear." (Session 1) In this context, music was considered very important and it was pointed out that it could be applied in all kinds of different areas (leisure, work, etc.). Hence, the main categories seem to be obsolete.

**Suggestions for improvement.** In order to simplify the navigation, it was suggested to remove the main categories and to provide a possibility to search for activities based on the health status of the person with dementia or his/her biography, i.e., to allow for personalized information retrieval.

In terms of task 3 (train communication strategies) and task 5 (emotional support) the basic functionality was demonstrated to participants and since hardly any active interaction was possible (e.g., responses were already pre-selected or participants had to simply click through the questions and only the correct answers could be selected), it was rather easy for participants to accomplish the respective tasks. Hence, it is hardly possible to provide information to what extent the participants could accurately and effectively complete the tasks.

#### 2.5.3 SUBJECTIVE SATISFACTION

With regard to subjective satisfaction, participants could indicate their overall satisfaction on a scale from 1 to 5 (1 = very satisfied, 5= very dissatisfied). Moreover, they could indicate what they liked or disliked when using the different functionalities. Scores were only indicated for task 1,2 and 4

(see also the comment above). Suggestions for improvement in this context refer to likes and dislikes we could identify during the evaluation.

# Task 1: Get guidance for specific situation

Participants' average satisfaction when interacting with the system to retrieve guidance for specific situation was 2,9, which indicates that they were averagely satisfied when using the system during task 1. It was rather difficult for most of the participants to find information about hitting, cursing, and memory loss. Other issues that were identified concern the information content and the lack of tips. Most of our participants were not satisfied with the content that is currently provided and pointed out that it is only **useful as "first information"** but not for somebody, who has already some years of experience in caring for a person with dementia. In almost half of the sessions (4), participants indicated that they **missed concrete tips** how they could behave in certain situations.

Suggestions for improvement. Considering, that most of the participants in our study had already a couple of years of experience in caring for a person with dementia, most of them said that more profound information should be provided and that they would appreciate direct links to valuable literature. Furthermore, links to organizations or persons, who could help were considered important. Moreover, it was suggested to provide medical information. Since people with dementia often face physical problems that go along with the disease, e.g., due to physical inactivity, some participants pointed out that it would be good to provide medical information, e.g., about bedsores, constipation or issues related to fluid intake, in order to avoid hospital stays. Also, medical documentation (e.g., blood pressure or medical intake) was considered useful. Finally, participants would wish for concrete tips how users could behave in such situations, i.e., not only background information, why participants show a certain kind of behavior, but tips to receive guidance for specific situations.

#### Task 2: Quick help

Participants were also averagely satisfied when using the system to retrieve quick help (average rating 3,1), because the service was difficult to find, which is illustrated in the following statements "It would be good to have a red button, this looks rather like a search field") (Session5) "This needs to be more eye-caching." (Session 9). Moreover, it was not clear why they should rate the tips they received at the end of the day. Some participants were questioning if other users could see their ratings.

**Suggestions for improvement.** Besides the suggestion to provide a more prominent button to retrieve quick help, it was suggested to include a possibility to directly contact a person, who could help in a situation where the user is overstrained. Moreover, users would like to have emergency numbers or information about organizations in the near vicinity they could contact in case of an emergency.

# Task 3: Train communication strategies

There were a few issues we could identify in terms of users' satisfaction about the training with an avatar, which mainly concern the gamification element. The meaning of the stars was not clear ("Why did I get stars?" Session 2) and some participants were doubting that the stars are motivating

to further learn or train communication strategies ("The stars do no harm, but I think I would be only motivated if the training would work." (Session 3). Moreover, a few participants said that they do not feel taken seriously and the stars do not fit in such a serious context ("I feel childish" Session 4, "I do not feel taken seriously." Session 3). One pair even laughed when they saw the stars and were wondering what would happen if they didn't answer all questions correctly. It also needs to be considered that not all participants could imagine training their communication strategies with a kind of avatar.

As a suggestion for improvement, it was recommended to make use of color psychology instead of the stars. Moreover, regular updates regarding the content would be required, also links to newspaper articles, books, literature or even events, which are considered important to learn and train communication strategies.

### Task 4: Meaningful activities

Participants average satisfaction when searching for meaningful activities was 1,7, hence most of them were rather satisfied. However, they were not satisfied with the examples that are currently provided (too simple). Moreover, the gamification element was not clear for some of the participants. "What is happening when I have earned some stars? This seems to be more a dalliance" (Session 5)

**Suggestions for improvement.** In order to improve the system, participants suggested to provide a bigger range of activities, one could choose from and meaningful descriptions (see also perceived usefulness). Furthermore, more concrete material, e.g., handicraft instructions were suggested.

#### Task 5: Emotional Support

In terms of emotional support, participants were rather satisfied with the content provided, however they did not like negative formulations. One participant did not like that the system asked questions s/he needed to answer: "This is again some work to do and I need to contemplate. I would rather prefer something that gingers me up. I could imagine that an avatar talks to me, saying: Well done today!" (Session 3).

**Suggestions for improvement:** Personalization was considered as an important element to increase users' satisfaction which is illustrated in the following quote: "Would be good to have the possibility to indicate activities, e.g., to take a bath to relax depending also on the condition on a particular day." (Session 8) As further suggestion for improvement, users asked for direct links to organizations or persons, where they could receive emotional support. Moreover, it was pointed out that it is important to make users aware that the burden (in terms of care) somebody is able to carry varies from person to person. One person suggested to implement an avatar, who could remind users of the app to take care of themselves.

#### 2.5.4 EASE OF USE

Overall, the results from our evaluation indicate that there is still potential to simplify the navigation and make the system easier to use. Particularly, get guidance and quick help were considered very difficult to use. For "get guidance" the main issue was the navigation, which was considered too complicated and too difficult to quickly retrieve information and for the quick information it was the visual design (a more prominent button would be required) and the navigation ("This is difficult, because I need to type in text" Session 1). Moreover, some participants had doubts, that they were able to search for appropriate terms in a stressful situation.

#### 2.5.5 PERCEIVED USEFULNESS

Besides usability issues, users' satisfaction and likes and dislikes when interacting with the system, we discussed with our participants to what extent the provided services were considered useful, considering their personal circumstance. The evaluation shows, that the content that is provided need to be adapted to the users' as well as participants' (PwD) needs. The main results with regard to the different tasks are described in the following paragraphs.

## Task 1: Get guidance for specific situation

Overall, all participants considered the function "get guidance" useful, however indicated suggestions for improvement to further increase the perceived usefulness.

**Suggestions for improvement.** First, the information that is provided **needs to be adapted to users' knowledge** about dementia, which is particularly important for professional care givers, how could only make use of "get guidance" if **more deeper insights** would be provided. Otherwise it might be only useful to recall knowledge about the disease. Second, participants lack **concrete tips,** indicating that not only information about the disease and its effects should be provided but that they would like to receive advice how they could behave in certain situations.

## Task 2: Quick help

In principle, participants considered the idea of the quick help useful, however the tips that were provided were considered only partly useful. Particularly the professional care givers had doubts that they would use that functionality, pointing out that it would be only useful for somebody who has not that much knowledge ore experience in dementia care.

**Suggestions for improvement.** Participants pointed out that the "tips" need to be more concrete and instructions need to be provided, for example "it is not indicated <u>how</u>! could calm down a person and what I could do if the tips do not work". (Session 6) "Concrete suggestions are missing … examples are important." (Session 7)

# Task 3: Train communication strategies

For most of the participants the idea of "training communication strategies" was considered useful, however it was pointed out that this should not be the main functionality of the app. Some participants even said that it is only a nice "add-on" or a "nice thing". For the moment, the content was too trivial and the questions too easy.

**Suggestions for improvement.** In order to use that functionality, more valuable content needs to be provided. Within one session, participant pointed out that the functionality only makes sense if the avatar was a person with dementia. S/he referred to Naomi Feil, who often takes the role of a person with dementia to illustrate how a person could behave and to discuss how to deal with such situations.

# Task 4: Meaningful activities

In general, participants considered the idea of suggestions for meaningful activities useful, however pointed out that the content that is currently provided might be only useful for somebody who has hardly any experience in caring for a person with dementia. Two persons, who are taking care of their mother for example said, "We actually have a lot of ideas for activities our mother likes." (Session 1) In another session (4) the participants pointed out that they would need other suggestions, because the examples that are provided are not quite elaborated and not quite specific.

Suggestions for improvement. With regard to the provided example (search for suggestions to remember past activities), two informal care givers said that they won't be able to look at photos or to go to places the person with dementia had been before, because the person they were taking care of was almost blind and not mobile anymore. They pointed out that the activities that are suggested need to be adapted to the health status of the person and the form of dementia the person is suffering from. ("There are so many forms of dementia." Session 1) Within another session it was discussed to consider the current context "It is actually wrong to simply suggest an activity, because I need to consider the current status of the person in order to decide what kind of activities could be useful. Suggestions are good however the central point is to avoid simply doing something ... this does not work for people with dementia. It is important to have help in order to decide which activity would suit for a certain situation" (Session 3) In order to provide meaningful suggestions, it was also considered important to study the biography of a person.

### **Task 5: Emotional Support**

Finally, the emotional support was considered as very useful functionality, however it needs to be further developed in order to allow users to understand how this part of the app could work. Participants, were, for example not sure who could read their answers and said that it could only work if more profound guestions are provided.

**Suggestions for improvement.** It was pointed out that links to organizations, literature, or persons were considered as valuable improvement and form of emotional support. For example, information about promotion and costs for home help, information that preventive care can be taken for up to 28 days a year and that costs for care during this time can be billed as prevention pledges, which allows caring people to go on vacation and to care for oneself.

#### 2.5.6 ACCESSIBILITY

The main accessibility problems that were identified during the study concern the font size and contrast (visual design). All participants indicated that the font size was too small and the labeling of items (e.g., when navigating through the menu of "get guidance for specific situations") was too small. Moreover, participants hardly recognized the "quick information" functionality. Moreover,

we could observer that particularly older users had difficulties to push the back button (too small). Moreover, the short distance between control elements (e.g., "get guidance": back button and physical aggression button) impeded the navigation.

Summing up, get guidance and quick help were considered as central functionalities, however participants missed *links to organization, literature, support groups, etc.* they could contact to receive help and guidance, in general as well as in case of an emergency. Moreover, *personalization* was identified as an important aspect that needs to be considered, i.e., informal and formal care givers might differ in terms of their experience and expertise in caring for a person with dementia and this should be considered when providing content (background information, tips). Moreover, *the individual biography, health status, current situation and general context* of the person with dementia needs to be considered when providing tips, e.g., for activities. This was also considered as an important aspect to increase satisfaction and usefulness of the provided services. A profile needs to be implemented that allow users to indicate this basic information. Besides the help and support functionalities, the emotional support was considered as important service from which formal as well as informal caregivers could benefit. *Gamification elements* that are currently provided were not quite comprehensive and hardly motivating, hence there is potential to improvement to encourage users to make use of the app.

# 2.6 IMPLICATIONS AND SUGGESTIONS FOR IMPROVEMENT

Table 2: Implications 1st Lab Trial

Service/function- ality	Issue	Description	Implications	
Get guidance	Information architecture	Too complicated overall navigation structure – too much levels to easily retrieve a result  Categorization is not decisive – e.g., physical sexual advances as subcategory of physical aggressive	Simplify navigation by, for example <i>reducing navigation levels</i> , to minimize users' memory load and <i>implement the shallowest possible information hierarchy</i> Allow users to <i>search for certain behavior</i> without the need to search for an appropriate main category (e.g. search for hitting instead of phycal aggressive / aggression / anger)	
			Search will be possible by means of a text field; results are displayed according to content type (open issue: easy operation through auto- complete and suggestions?	
			Filter option: based on content type	
	User freedom	Need to select multiple items at once to receive a result	Optional: allow for multiple choice	
			→ Not needed due to changes in overall navigation and filter options	
	Visual design	Not all buttons were recognized as buttons, e.g., back-but-	Design for <i>clickable elements</i> – consistent design	
		ton and violet globes  Get guidance was not associated by all participants with re-	→ Will be considered for the next prototype	
		trieving information about hitting, etc. → alternatively train communication and emotional support were selected	To be discussed: labelling of main categories (e.g., Help, Train, Activities)	
			New labelling of main categories: Learn and train, Activities, Emotional Support, quick advice	

	Accessibility	Small distance between control elements impeded navigation (users accidentally pushed two buttons at once)	Increase distance between control elements – consider older users' needs in term of the size of buttons
		Text is too small	Allow users to increase the text — consider older adults' needs in terms of font size
			Accessibility issues will be considered for the next prototype / first integrated version
	Content	Need for concrete tips (e.g., how to behave in certain situations)	To be discussed: merge information part and concrete tips  → Concrete tips will be part of articles
		Need for additional information - basic medical information, links to literature, books as well as organizations	To be discussed: where / how to provide this information  Will be added to content elements where required
		Content that is currently provided might be only useful for somebody, who has hardly any experience in the field of dementia care	Content in progress
		Dementia has a variety of different faces – needs to be considered when providing content	Allow to personalize content / indicate basic information in the profile (e.g., form of dementia, stage)
		sidered when providing content	It will be possible to indicate the form of dementia in the profile
Quick help	Information architecture	Typing in some text to retrieve results might be overstraining in a stressful situation	<b>Minimize users' memory load</b> - support users to find results based on e.g., suggestions for categories, terms or situations (content needs to be discussed)
			→ Research on alternative possibilities for a search function
			→ In a first instance the search field will be implemented
	Visual design / match be- tween system and real world	Users could hardly find the service quick advice — text field does not fit users' mental model to retrieve quick help	Make use of virtual objects that allow users to easily understand the meaning of the service (text field implies "simple search") - e.g., use a more prominent button, e.g., red button
			→ A more prominent button will be implemented

	Content	person / expert) and information about organizations in the near vicinity	To be discussed: Feasibility to include phone numbers of key persons /experts or contact details about organizations in the near vicinity?  → Will be not implemented; users might have important phone numbers anyway available in their contacts on the mobile phone
		Need for more concrete tips	Content in progress
Train communication strategies	Visual design / Content	The meaning of gamification elements (stars) is hardly understood / some participants do not feel taken seriously	<b>To be discussed:</b> What are gamification elements that fit user's mental model for gratification in this context?
			→ Dashboard to track progress
			→ Quiz elements to allow users to repeat content elements
	Information architecture	How to search for certain communication strategies? What are "challenges"	<b>To be discussed:</b> How should the overall functionality look like? What is the role of the avatar?
			→ When starting the application, the avatar will ask the user how s/he is doing and what s/he has done to feel good; afterwards option to work on reflection (scripts Sienna), second element: diary (motivated by the avatar, who regularly ask e.g., to perform activities
	Content	Questions that are provided are too easy / content needs to be more elaborated	Content in progress should provide aspects of "validation", links to courses
Meaningful activities	Information architecture /	Categorization of activities is not decisive (music could be part of leisure as well as work)	<b>Rework the navigation</b> – allow to search for activities based on personal criteria, e.g., health status or a user's biography
	Content	Health status or a user's biography seem to be important factors to decide for an appropriate activity	→ The profile allows to indicate form of dementia, capabilities (physical and mental) and interests — based on this, activities are suggested (requirement: tagging content elements)
	Visual design	Difficulties to recognize if further information about a certain activity is provided	Allow to better <i>recognize clickable elements</i> → Will be considered for the next prototype

	Content	Gamification element (stars) is hardly understood by participants – not clear why they receive stars when searching for an activity	To be discussed: What are gamification elements that fit user's mental model for gratification in this context?  → See also suggestions above
		Current suggestions for activities are too trivial – needs to be more elaborated	Content in progress provide more concrete and elaborated suggestions for activities considering a person's health status, etc. (see comment above)
Emotional Sup- port	Content	Need to personalize content (e.g., to indicate activities they would like to do)	Content in progress
		Users expect to receive emotional support from organizations or experts in the field of dementia care	<b>To be discussed:</b> direct links to organizations / persons who could provide emotional support – need to be discussed where / how this information could be provided
		Need for literature, information and other forms of emotional support	<b>To be discussed:</b> how / where could we provide links to literature, information about organizations where users can get emotional support
		Texts are currently considered too academic	→ Will be part of content elements where required/useful
			→ Links to avoid that users end up on an empty page (e.g., if no further content is available)
			Content in progress

# 3 SECOND USER STUDIES IN THE LABORATORY

Based on the results from the first user study in the laboratory the UI was further developed and improved. Whereas, for the first trial a low-fidelity prototype was available, the second trial allows to test the first integrated version.

# 3.1 GOALS

The main goals of the second lab trial was to evaluate the improvements made based on the first trial, i.e., we aim at assessing usability and accessibility problems. Moreover, since a first integrated version was available, allowing users to explore the interaction with an avatar in lectures and role plays, we explored users' experiences and needs in terms of the avatar design, considering the different types of content (lecture and role play). Moreover, some participants were asked about their opinion towards the business model (e.g., willingness to pay for a service that could support them in the field of dementia care). These questions were provided by Exthex.

# 3.2 METHODOLOGICAL APPROACH

We applied a mixed-method approach with potential end users (formal and informal care givers), which was constituted by two main parts:

- 1) **Usability testing**. Participants carried out pre-defined tasks and they are asked to thinkaloud while performing the tasks. Like in the first trial we focus on performance measures (task time and task completion, see also Dumas, 2002) and subjective measures (user satisfaction, likes, dislikes). (for a detailed description see also section 2.2)
- 2) Co-design activity: Before interacting with the avatar, participants were asked about their expectations towards the avatar. (If they experience difficulties to imagine certain criteria, several design prompts were provided.) Users were asked to define the most three important characteristics/criteria with regard to the avatar design. Thereby, the two different situations (lecture, role play with a PwD) were considered. The avatars were presented to the participants and they were asked to carry out the respective tasks. Afterwards, it was discussed to what extent the avatar meets the expectations and how the avatar could be improved (co-design activity).

#### 3.3 STUDY SETUP

The second lab trial was constituted by two main parts: the usability testing and the co-design activity. A brief description of the overall procedure is provided in the following paragraphs.

In the run-up phase to the study, participants received information about the overall project idea and the procedure of the study (place, duration, etc.). The study participants were recruited by the two end user organizations in the project (EURAG, RAS). Ten end users (primary end user group) per country were recruited (5 formal care givers, 5 informal care givers). Participants had experience in caring for people with dementia and were smart phone users. Participants, who were part of the first user study in the lab and still had interest in contributing to the further development were also invited to take part.

# 3.3.1 INTRODUCTION TO THE STUDY

When participants arrive, they were briefly introduced to the study (overall information, procedure and methodology - think aloud). Open questions (if there were any) were clarified. Moreover, participants were asked to fill out a brief questionnaire, assessing basic demographic data (age, gender, highest education, ...) and mobile phone usage (Android, iOS).

#### 3.3.2 PRE-INTERVIEW

Before starting with the task, the test leader gathered information about participants' experiences with people with dementia (guideline-based interview). Participants, who already took part in the first evaluation were not asked again (see also section 2.3.2). Moreover, some questions towards the business model were asked (see section 3.1)

#### 3.3.3 TASKS

After the pre-interview, the test leader handed out the smart phone and introduced the participant to the tasks (task by task). The participant was reminded to talk about his/her thoughts while carrying out the task. During the tasks, the test leader observed how the tasks was carried out (e.g., how the user solved the tasks, if s/he experienced any problems in solving the task, etc.) and took notes; after each task the participants were asked to answer a few questions (e.g., how easy s/he could carry out the tasks, if problems occurred and why, if they have any suggestions for improvement). Each task was based on a small scenario to support the participants in imagining a certain situation. Thereby, we considered both target groups (formal and informal care givers).

#### Task 1: Learn about dementia

Scenario 1A (formal care giver): You have got a new client, Maria Waltersberger, who has been diagnosed with dementia a few months ago. You have knowledge and experience in dementia care in general, but it's been a while since you have taken care of somebody. Your colleague told you about a new dementia app that allows you to learn more about this disease and to train your skills. You decide to use the app to brisk up your knowledge about dementia. You open the app for the first time and explore, what you can learn about dementia. Please explore the app and afterwards return to the home screen.

**Scenario1B** (informal care giver): A few months ago, your mother was diagnosed with dementia. The diagnosis was a shock for you and you often feel overwhelmed when caring for her. A friend of you told you that there is a new app available that allows you to learn more about the disease and to train your skills. **You open the app for the first time and explore, what you can learn about dementia. Please explore the app and afterwards return to the home screen.** 

#### Questions 1A/B:

- → How easily could you find information about dementia care? (ask why users could easily find / or could not easily find that information)
- → What do you think? How could the app support you to learn more about dementia and dementia care? (the interviewer asks for different content elements, observes if users already understand how to search for content elements- text field, filter function, ask why they proceed in a certain

way – e.g., using the search field or using the filter option for content elements, what did participants like / dislike?)

→ Do you have any suggestions for improvement? (ask for concrete suggestions – what would users change?)

# Task 2: Search for an article about false accusations

**Scenario 2A** (formal care giver): Since a couple of weeks you are taking care now of Maria Waltersberger and you got to know her better. You observe that she is often hiding things, forgets where she has put the objects, and afterwards becomes angry and accuses you or other persons that they have stolen something. You always try to keep calm and assures her that everything is alright. Sometimes it works – sometimes not. You decide to see if the app could provide some useful information. *Please find out more about the behavior "false accusation" and how you could react in such situations. Afterwards return to the home page.* 

**Scenario 2B** (informal care giver): Since a couple of weeks you observe that your mother is hiding things, forgets where she has put those objects, and afterwards accuses you that you have stolen something. You always try to keep calm and assures her that everything is alright. Sometimes it works – sometimes not. You decide to see if the app could provide some useful information. *Please find out more about the behavior "false accusation" and how you could react in such situations.* **Afterwards return to the home page.** 

## Questions 2A/2B:

- → How satisfied were you when using the system? (Rating on a scale of 1-5?1 = very satisfied, 5 = very dissatisfied) (ask why users were satisfied / dissatisfied)
- → Could you find some useful information? / How easily could you find the required information? / Did you miss information? (explicitly ask what they missed, or why it was difficult/not difficult to find the information)
- → Do you have any suggestions for improvement? (if yes, what would you suggest to change?)

# Task 3: Quick Info

**Scenario 3A (formal care giver)**: It is Monday morning, you just have prepared breakfast for Maria Waltersberger. The last weeks her memory loss was getting worse. While you are sitting with her at the table, eating breakfast, she is now asking you the 8<sup>th</sup> time if her son will come to visit her this week. You feel somehow overstrained and are not sure how you could react, however there is no time to read an article. You decide to scroll through the quick info to find some useful tips. *Please retrieve some quick info for memory loss. Afterwards return to the home page.* 

**Scenario 3B (informal care giver)**: Since a couple of weeks the memory loss of your mother gets worse. While you are sitting with her at the table, eating breakfast, she is now asking you the 8<sup>th</sup> time if her son will come to visit her this week. You feel somehow overstrained and are not sure how you could react, however there is no time to read an article. You decide to scroll through the quick info to find some useful tips. *Please retrieve some quick info for memory loss. Afterwards return to the home page.* 

#### Questions:

- → How satisfied were you when using the system? (Rating on a scale of 1-5?1 = very satisfied, 5 = very dissatisfied) (ask why users were satisfied / dissatisfied)
- → How easily could you find the required information? (why? / why not?)
- → To what extent are the tips useful? (if yes/no why was it useful/not useful?)
- → Do you have any suggestion for improvement?

# Task 4: General expectations towards the avatar

Besides articles and quick info, the app provides more interactive forms of learning. Thereby, interactions with an avatar (virtual presentation of a person) will be possible. On the one hand, an avatar will provide lectures about certain topics on the other hand you can train your behavior and skills in a role play with an avatar, whereby, the avatar represents a person with dementia. Before, you will get the opportunity to try out these interactions, I would like to talk with you about your general expectations towards an avatar.

#### **Questions:**

→ Do you have any general expectations towards an avatar?

#### *Instruction for the interviewer:*

- Ask for appearance, specific characteristics the users would expect (and for the reason why are certain characteristics important for the person?)
- Users are asked to write down those expectations on post its. (If users have a variety of different expectations, ask to rank them according to priority)
- Different designs of avatars are presented to the participants to better discuss ideas/expectations

#### Task 5: Avatar lecture (meaningful activity/work)

**Scenario 5A (formal care giver):** Imagine, you are in the office doing some paper work. You still have some time before the end of the working day, so you decide to look at one of the avatar lectures to learn more about dementia care. One area you haven't had a look so far is how you could carry out meaningful activities for and with the person with dementia. Hence, you decide to hear a lecture.

**Scenario 5B (informal care giver):** Imagine you are at home and have some free time. You decide to look at one of the avatar lectures to learn more about dementia care. One area you haven't had a look so far is how you could carry out meaningful activities for and with the person with dementia. Hence, you decide to hear a lecture.

### Questions 5A/5B

→ If you think about an avatar giving that lecture, are there certain expectations you have towards that avatar?

#### Task 5A/5B

→ Please start the lecture about meaningful activities / work. Afterwards, please return to the home page

# Questions 5A/5B

- → How satisfied were you when using the system? (Rating on a scale of 1-5?1 = very satisfied, 5 = very dissatisfied) (ask why users were satisfied / dissatisfied)
- → To what extent was the lecture useful to you? (why? /why not?)
- → Do you think you could benefit from such a lecture? (why? / why not?)
- → If you think about your expectations towards an avatar; to what extent does the avatar meet those expectations? (why? / why not?)

# Task 6: Role play (Physical aggressive behavior)

Scenario 6A (formal care giver): Since approximately 6 months, you are now taking care of Maria Waltersberger. Whereas in the beginning she often lost things and you were confronted with false accusations, she is now getting more and more aggressive. It is a completely new situation for you and you often feel overwhelmed. You always try to stay friendly and avoid taking things personally, but it is quite difficult for you and you would wish for some advice how to better react and behave, when she becomes aggressive. The app allows you to train behavior and skills with an avatar and you decide to try out this functionality.

Scenario 6B (informal care giver): It now quite a while ago since your mother has been diagnosed with dementia. Whereas in the beginning she often lost things and you were confronted with false accusations, she is now getting more and more aggressive. It is a completely new situation for you and you often feel overwhelmed. You always try to stay friendly and avoid taking things personally, but it is quite difficult for you and you would wish for some advice how to better react and behave, when she becomes aggressive. The app allows you to train behavior and skills with an avatar and you decide to try out this functionality.

#### Questions 6A/6B

- → If you think about an avatar visualizing a person with dementia, are there certain expectations you have towards that avatar? (if yes, what are your expectations?)
- → Do you think you could benefit from such a roleplay (why? / why not?)?

# Task 6A/5B

→ Please start a role play about physical aggressive behavior. Imagine that the avatar is a person with dementia, who shows aggressive behavior. Through voice input/text input you can react

and can try out different behaviors. Within the scenario which is provided, you should convince the person with dementia to go to the bathroom.

#### Questions 6A/6B

- → How satisfied were you when using the system? (Rating on a scale of 1-5?1 = very satisfied, 5 = very dissatisfied) (ask why users were satisfied / dissatisfied)
- → To what extent was the role play useful to you? (why? /why not?)
- → Do you think you could benefit from such a role play? (why? / why not?)
- → If you think about your expectations towards an avatar; to what extent does the avatar meet those expectations? (why? / why not?)
- → If you think about your expectations towards a roleplay avatar, how apposite do you find the depiction of the avatar as a person with dementia? (why? / why not?)

**Post Interview/Debriefing** After the participants have completed the tasks a brief guided interview takes place. The test leader will clarify open issues and will ask the participants to indicate their overall satisfaction (e.g., likes, dislikes) towards the system. Suggestion for improvement are further elaborated, focusing on user needs in terms of the avatar design.

## 3.4 ORGANIZATION

## 3.4.1 RECRUITING PROFILE

Overall 20 primary end users will be recruited (5 formal and 5 informal care givers in Austria and in Romania). The following selection criteria are considered:

- At least one year of experience in caring for people with dementia
- Smart phone usage (preferred android users)

#### 3.4.2 TIMELINE AND RESPONSIBILITIES

Table 3: Timeline and responsibilities of the 2<sup>nd</sup> user study in the laboratory

Calendar week	Activity	Responsibility
CW6,7 (5.2. – 15.2.2018)	Concept development, definition of tasks, translations	AIT, TE, EURAG; RAS
CW8 (19./20.02.2018)	Final integrated prototype is provided	Center for Health & Bioresources
CW8 (19.0223.02.2018)	Recruitment, finalized translations, preparation of materials	AIT, TE, EURAG, RAS
CW9 (27.02-01.03.2018)	Pre-Test, Implementation	AIT, TE
CW10 (04.03 – 08.03.2018)	First Results prepared for consortium meeting	AIT, TE
CW11/12 (12.03. – 16.03.2018)	Analysis and report	AIT, TE

#### 3.5 RESULTS

In this chapter the main results are briefly described and most important implications for the further development of the app are outlined. Performance measures (e.g., task time and task completion), subjective measures (user satisfaction, likes, dislikes), and participants' expectations towards the interaction with the avatar are reported regarding the respective tasks.

#### 3.5.1 PARTICIPANTS

Overall, 20 participants (10 in Austria, 10 in Romania) took part in the user evaluation in the laboratory, both formal and informal care givers.

In Austria, participants were between 23 and 67 years old (M= 53,11, SD=12,13). The majority was female (80%) and 20% were male. More than half of the participants (60%) indicated that they had at least a general qualification for University entry, 40% indicated "professional school" as highest education, and nobody indicated elementary school as highest education. Four formal care givers (experts in the field of dementia) and six informal care givers (friends, family members) took part in the evaluation.

Almost half of the participants (40%) were still full-time employed, one fifth (20%) was working part-time, and 40% indicated that they were not employed, i.e., were already retired or unemployed. In terms of experience in the field of dementia care, all participants had at least approx. one year of experience.

In Romania, participants were between 49 and 77 years old (M= 59,32, SD=10,08). The majority was female (90%) and 10% were male. All participants indicated that they had at least a general qualification for University entry as highest education. Six participants had indicated that the highest form of educational achievement was other than the options included, for one this meaning holding a PhD diploma, three have finalized MA programs, one underwent residency training (participant was a MD) and one had a post high school degree. One formal care giver (expert in the field of dementia) and nine informal care givers (family members) took part in the evaluation. Almost half of the participants (40%) were still full-time employed and 60% indicated that they were not employed, i.e., were already retired or unemployed. In terms of experience in the field of dementia care, all participants had at least approx. one year of experience.

Participants, who have not been involved in an evaluation beforehand were asked if they had ever installed an app on their smart phone that could support them in terms of health care and if they would be willing to pay for an app that provides advice and daily support when caring for a person with dementia. Overall seven users in Austria and ten users in Romania were interviewed. None of the seven participants had ever installed such an app before. Five of the Austrian users and all of the Romanian ones indicated that they could imagine paying for such an app if it is proven to be useful. Thereby, the expectations in terms of the prize and terms of payment were quite diverse. For a single payment, the Austrian participants would be willing to pay between 20€ and 50€. Furthermore, it was suggested to provide a kind of license model, hence, the care facility should pay a certain amount and employees receive a license for free. In general, it was quite difficult for users to answer these questions because they hardly used any apps, hence could not imagine the benefit they could gain nor anticipate how much they would be willing to pay. Romanian participants

also had difficulties indicating a price, but they suggested would be willing to pay a price similar than what is asked for other similar apps or the price they would pay for a book.

#### 3.5.2 EFFECTIVENESS & EFFICIENCY

#### Task 1: Learn about dementia

Task 1 aimed at investigating to what extent the participants could easily find general information about dementia care, hence we focused on the evaluation of the overall navigation structure. The results illustrate that all participants could easily and quickly manage to find general information about dementia care and did not need any help to solve the task. Most of them directly navigated to "learn and train". Only two participants, who made use of the quick info in this context and experienced difficulties when using the search (see also section 3.5.5).

Suggestions for improvement. It was suggested to provide information/feedback about articles the user has already read, which would make it easier to quickly and easily recognize new articles. One participant, for example, suggested to mark articles that have been read with a checkmark; another participant indicated that s/he would number the articles to recognize when a new number was added. Finally, it was suggested to provide an option for the user to highlight certain text elements, or even the article to make it possible to easily find certain content elements again. (e.g., elements users considered particularly useful).

#### Task 2: Search for an article about false accusations

All participants could easily and quickly find the article about false accusations. A few difficulties were recognized with regard to the search (either participants did not immediately recognize the option (search field) or were not aware that the results are immediately displayed while typing. Users expected to confirm an entry (e.g., by pushing the enter button), which is illustrated by a statement of one participant: "I would need to get used to that form of searching ... If I type in a word here ... It is quite automatically, I type in a word and then press the enter button. It is of course nice that results are immediately shown ... Probably the menu bar between the search and the result is disturbing, I mean regarding the visual perception." (TN6). Another participant indicated that it is important to know how to search, meaning that one needs to know which terms need to be used to receive a result.

**Suggestions for improvement.** As suggestion for improvement it was recommended to provide enough **key words** for an article to quickly retrieve a result. Moreover, it was suggested to **allow navigating to the articles by clicking on the feedback bar** on the home screen (indicating how many articles users have already read). Also, in order to improve the recognition and use of the search bar, it was recommended to add a **magnifying-glass icon** to the search bar.

# Task 3: Quick Info: Memory loss

More than half of the participants could not efficiently solve the task, because they did not find the required button and needed a hint (provided by the test leader). Some participants, for example, tried out the "learn and train" to find some tips, one participant clicked on "meaningful activities",

because s/he wanted to find an activity to distract the PwD. No concrete suggestions to improve effectiveness and efficiency were mentioned by the participants.

## Task 5: Avatar Lectures (meaningful activity/work)

To solve the task, participants were first asked to find the avatar lecture about meaningful activity/work on the mobile phone. The lecture was afterwards demonstrated on a laptop, since at this stage of the project the functionality did not work on any mobile device. Most of the participants could not quickly solve the task and needed help/support from the test leader. A few participants already struggled with the navigation on the smartphone. One participant tried to select lecture via the feedback bar on the home screen (which was not possible). There were also a couple of issues identified when users tried to start the lecture and to navigate within the lecture. Users sometimes tried to start the lecture by clicking on the text field on the bottom of the screen not the green button. Moreover, they experienced difficulties to retrieve the main topics (work, leisure, etc.) and to go back to the main menu (same buttons as in the interaction with the avatar were used.

## Task 6: Avatar Roleplay (physical aggression)

Similar as in task 5, participants were first asked to find the role play about physical aggression on the mobile device and afterwards the role play was displayed on a laptop. Three participants needed help to solve the task, most of them experienced the overall navigation difficult. There were problems when starting the avatar lecture, as illustrated by means of the following example statements: "Do I need to say something of does the avatar start? Where do I see possibilities to give an answer?" (TN2) "Do I need to select the first answer?" (TN6) "If it works like this in reality ... then congratulations ... (ironically meant) I do not think that this will work." (TN9). In terms of the navigation the same problems like in the avatar lecture occurred (not clear how to select the answers – rather selected the text field than the green button). Moreover, the font size was again too small.

#### 3.5.3 SUBJECTIVE SATISFACTION

#### Task 1: Learn about dementia

Participants' average rating regarding satisfaction was 1,9 in Austria and 1,1 in Romania indicating that they were rather satisfied when searching for general information about dementia. Some participants experienced dissatisfaction in terms of the structure of the articles, indicating that the lack of paragraphs impeded to easily read the articles. One participant did not like that certain phrases were used again and again within different articles. "If you read the same thing again and again in becomes boring. There is exactly the same sentence as before." (TN9). For some of the articles the text boxes did not adjust to fit the text which created a sketchy feeling.

**Suggestions for improvement.** Most improvement suggested by the users concern the **structure of the articles.** Here it was recommended to provide **paragraphs, headings, or highlight important terms** to make it easier for the users to retrieve relevant information. Furthermore, it was suggested to use **pictograms instead of pictures**, because they were considered easier to understand and more meaningful. In terms of the wording of articles (it

seems that there is always the same content provided) it was suggested to **reformulate those parts of the articles**.

#### Task 2: Search for an article about false accusations

Participants' average rating of satisfaction was 1,5 in Austria and 1.2 in Romania, indicating that participants were rather satisfied when searching for an article about false accusations. Again, participants pointed out that the articles are hardly to read due to the lack of paragraphs, headings, etc. (see also the comments above).

**Suggestions for improvement.** As suggestion for improvement, participants mentioned to provide a clear structure for the articles (using headings etc. – see also the suggestions or improvement with regard to task 1).

### Task 3: Quick Info: Memory loss

Participants' average rating for satisfaction was 2,5 in Austria and 1.8 in Romania, indicating that they were only moderately satisfied when solving the task indicating that they lack a clear navigation structure and more concrete tips. Moreover, it was difficult for them to read the tags (white font on a grey background) and they were dissatisfied because not only relevant results were shown (e.g., when searching for aggression other results were displayed.

**Suggestions for improvement:** To increase the user satisfaction, it was suggested to **provide** more concrete tips.

## Task 5: Avatar Lectures (meaningful activity/work)

Users overall satisfaction with the avatar lecture was 3,3 in Austria and 2.4 in Romania indicating that they were rather dissatisfied. They were dissatisfied with the illustration of the avatar (movements as well as voice and general illustration). Participants experienced, for example, that the voice does not go along with mimic and gestures of the avatar, that there are too much movements, which are distracting, and that movements are strange and do not fit to the overall situation. One participant experienced the male avatar as being unkempt. "I won't believe such a type of person" (TP6) Moreover, it was indicated that the font in the boxes displayed beyond the avatar was hardly to read. For some participants it was somehow distracting to read the text, others would prefer reading only the text ("I would not need the avatar ... I could only read that" TN4) the avatar was talking; one participant appreciated the possibility to read the text. "It is good to listen and read at the same time ... However, the font is too small and there are no paragraphs." (TN6) Some participants had the feeling that the voice sounded jerky and tiring like the voice of a robot. Finally, participants experienced difficulties to navigate through the menu.

**Suggestion for improvement:** It was suggested to provide a possibility to **pause the lecture** and to provide feedback for the user in terms of the length of a lecture given. Moreover, participants would wish **for improvements in terms of the illustration** of the avatars (realistic animation of behavior, appropriate clothing and appearance).

## Task 6: Avatar Roleplay (physical aggression)

Participants indicated a moderate satisfaction when playing the roleplay (2,4 in Austria and 1.6 in Romania). Most comments were made about the navigation. It was not clear when they needed to press the green button and how the overall navigation worked. The meaning of the blue arrows was not clear and most of the participants did not understand how they could select the different responses. The observations show that a lot of participants practiced "trial and error" to start a lecture and to navigate through that part of the app.

**Suggestions for improvement.** In order to increase users' satisfaction, it was suggested to **reduce movements of the avatar** to make it easier to listen (movements are somehow distracting, because movements are not realistic and do not fit the situation) and to **simplify the overall navigation**.

#### 3.5.4 EASE OF USE

#### Task 1: Learn about dementia

Participants indicated that it was very easy to find the required information (general information about dementia care) due to the clear navigation structure on the home screen. A couple of participants had difficulties to recognize how many articles they have already read. Moreover, some participants considered the feedback bar (e.g., 6/8 – indicating that 6 from 8 articles have already been read) as menu and tried to navigate to the articles by clicking on it. There were also difficulties identified with regards to the filter function. All of the participants tried to select the category article by clicking on "article", which is illustrated by a statement of one participant: "It is not clear for me how that actually works. I would press the button "article" to select it and not deactivating all other categories." (TN9). Finally, in the main menu the category "self-reflection" seemed to be not self-explaining without any content. One participant was wondering what kind of functionalities are provided there. Those two participants, who tried out the quick info to retrieve information about dementia care did not understand how the pop-up windows and the list of recommendations fit together. "It is confusing that there is both – pop-up and a list – this does not fit together!" (TN19)

# Task 2: Search for an article about false accusations

Apart from the difficulties regarding the search we could not identify any additional problems in terms of ease of use.

#### Task 3: Quick Info: Memory loss

As already mentioned above, not all participants could easily find the required information. The examples, provided in the following, illustrate the main problems that occurred. Some of the participants were not aware that they needed to make use of the search (did not even recognize the search field), hence, what they saw in a first instance was only a random list of tips. Hence, they indicated that they lack a clear structure to find a quick tip. and "only" scrolled through the list. Other participants used alternative words to "memory loss", e.g., one typed in "forgetful", hence did not receive any results at all. S/he accidentally found the pop-up and was not sure how the list with tips and the pop-up fit together. Again, participants experienced problems to retrieve results

from the search, trying to find a kind of "enter-button". This can be illustrated by means of the following statement: "It is awkward ... I actually do not know what I can do to fade out the keyboard again. It is not useful to quickly retrieve help" (TN10)

## Task 5: Avatar Lectures (meaningful activity/work)

More than half of the participants needed help to solve the task and struggled with the overall navigation. First, participants had difficulties to find the lecture in the overall menu, related to the complicated filter function. Hence, they could not easily find the required information. Participants experienced difficulties to recognize the meaning of the buttons provided for starting a lecture and selecting different topics (did not recognize that they needed to use the green button to start the lecture) and had problems to navigate back to the main menu. In order to start the lecture, a lot of participants clicked on the white text field (without success). The observations show, that most participants could only solve the task by "trial and error".

## Task 6: Avatar Roleplay (physical aggression)

A lot of participants experienced difficulties to start the lecture. The filter function was confusing (see also task 1 and task 2) and most of them did not understand the meaning of the green button (start the role play) and how they could select different topics (see also task 5). Participants tried to select the topics by clicking on the text fields. Moreover, it was not clear for them how to stop the role play (a few participants tried to stop it by clicking on the back button). Hence, in general, participants could not easily solve the task.

#### 3.5.5 USEFULNESS

#### Task 1: Learn about dementia

In general, most of the participants indicated that the content that is provided is useful. One participant for example said "It is helpful without any doubt. You forget things in your day-to-day life, so it is nice to have something that reminds you." (TN1) One participant, who was working in a hospital context indicated that s/he lack a reference to the hospital context. This participant was also guite critical in term of the advices given. S/he indicated that she does not agree to the advice to close rooms, because PwD should be able to freely move. The advice "We will go home tomorrow" (if a user insists to go home) was considered problematic, because it might be that patients remember such statements until the next day. In terms of lost objects, this participant indicated that it would be good to ask how the object looks like, because some PwD might remember if or where the object could be. The links that were provided were considered partly useful. One participant said that links are difficult to find. "I always need to go back to an article to access the link again. It would be great to have a separate category, where useful links, addresses or even events, e.g., lectures are provided ... It would be good if I could find other people who also care for PwD and to have a possibility to exchange experiences." (TN10) [The participant did not recognize that always the same links are provided]. Another participant recognized that always the same links are provided and indicated: "Links should always refer to a specific article ... so if there is information about wandering there should be links that concern to the topic wandering." (TN6)

Another user suggested that "the articles could be more structured in order to be easier to follow (e.g. description of the problem, behavior PwD, strategies employed by carers; concrete example)".

**Suggestions for improvement.** Participants indicated that it would be useful to **make links available independently from the articles** to support users to easily and quickly find them again if needed. Moreover, it was suggested to provide a kind of "**information area**" where useful addresses, events, lectures, links to self-help groups or forums are provided to support users to easily find other people with whom they could exchange experiences. It can be also beneficial to revise and complement the articles, based on the feedback given.

#### Task 2: Search for an article about false accusations

All participants considered the information useful. "The information is very useful, there are practical advices ... there are not lofty words ... the examples are taken from real life." (TN2). One participant had concerns that s/he could only make use of those advices when s/he has enough time. Another participant indicated that she does not agree with the content provide: "It is not good to tell the person that everything is alright! In this specific situation nothing is alright and such a statement could evoke aggression. The person is to be taken seriously, hence it is important to inquire ... I would feel fooled ... It is important here to practice validation. "(TN5)

## Task 3: Quick Info: Memory loss

Only two participants explicitly indicated that they consider the tips useful (one of these participants could solve the task without any help). A few participants said that from their perspective the tips are only useful in combination with the articles and one participant gave an example that illustrate the problem: "Try to find out what the reason is why the person is wandering. That might be difficult for a person, who is not an expert in this field of dementia care." (TN5). One person did not recognize the pop up, scrolled through the list and said that s/he think it is not useful because s/he would need to read too much, before receiving concrete advice. Moreover, s/he considers the tips incoherent. Another participant pointed out that s/he feels awkward, if she looks up information on the smart phone, while caring for a PwD. "It is important to focus on the patient ... you cannot show appreciation and respect when staring at your smart phone ... moreover, I won't be allowed to use my smart phone during work, so probably an iPad would be good." (TN6)

Suggestion for improvement: Participants mentioned a variety of suggestions to improve the quick info. A few suggestions concern the overall design, e.g., one participant suggested to increase the size of the quick info button. Another participant recommended to select another color than red for the pop-up window, indicating that s/he expects the quick info to calm her down and that the red pop-up window rather makes her feel upset. Furthermore, it was suggested to improve the structure of the tips (allow users to recognize to which overall topic the tip refers). This suggestion was particularly mentioned by those participants, who did not recognize at a first glance the relation between the list of tips and the pop-up. Finally, as an important improvement it was mentioned to provide more and good keywords to support users to retrieve a result and to provide only tips that are relevant for the person one is taking care for. There was also a comment in terms of the wording of the quick info. One person pointed out that s/he would avoid using the imperative, because it

indicates that you have to do something to avoid making a mistake. Instead of "Do not judge the PwD!" it is better saying "It is important to avoid judging a PwD".

# Task 5: Avatar Lectures (meaningful activity/work)

In principle, most of the participants considered the lecture useful. There were three participants, who indicated that they could not benefit from such a lecture. One participant said that s/he already knew a lot about dementia, hence the content would need to be more demanding. Two participants said that the content needs to be more practical and adapted to individual users they are caring for and their stage of dementia. One participant was that distracted by the appearance of the avatar that s/he could not remember what the avatar said. Those participants, who had the feeling that they could benefit from the lecture indicated that it is not that demanding than reading a text and that it is nice if you have some time to listen.

**Suggestions for improvement:** In order to increase the usefulness of the lectures it was suggested to **consider different stages of dementia**, so that users with different levels of expertise could benefit and to provide practical tips like games. One participant indicated that s/he would appreciate having the content also available as text.

# Task 6: Avatar Roleplay (physical aggression)

Most of the participants, considered the role play useful, e.g., "It is a god idea that the avatar can react to an answer." (TN1) Thereby, is was indicated that it is a good opportunity to train and practice behavior with people with dementia. Two participants were skeptical that they could benefit from such a form of training. One expert pointed out that s/he considers the training only useful for informal care givers, who do not have that much experience in the field of dementia care.

**Suggestions for improvement:** In order to increase the usefulness of such a role play, it was suggested to provide more response options.

## 3.5.6 ACCESSIBILITY

In general, participants hardly experienced any accessibility problems. Only one participants tried to "zoom in", expressing the need to increase the font size. However, most of the participants considered the font size adequate in the overall menu (difficulties to read text were identified in the role play and lecture, where the information provided in the text fields was sometimes hardly readable, depending on the amount of text that was provides —the more text, the smaller the font).

# 3.5.7 GENERAL EXPECTATIONS TOWARDS AVATARS

The expectations towards the avatars were quite diverse. We asked participants to indicate what they would expect from an avatar, who provides a lecture and an avatar, who illustrates an older person with dementia. The interviews show, that there are no specific preferences regarding sex. Participants could imagine the avatar to be both, male and female. Some expressed the need to select sex or even ethnicity. In terms of age, participants expected that the avatar who provides the lecture should not be too young (approx. 40-50 years); one participant indicated 30-40 years. For

the patient with dementia it was considered important that the avatar fits an old person with dementia. Quite differs expectations were identified towards the illustration of the avatar. Some participants said that they would prefer a rather realistic design, however there were also hesitations that a too realistic animation of behavior could be "too much" (TN8). This participant indicated that a too realistic animation could have a strong impact on sympathy or antipathy. In terms of the avatar, who provides a lecture the following attributes were mentioned: pleasant voice, trustworthy, reliable, open, pleasant, good pronunciation, speak fluently, nice person, should have a name, well-groomed, nondescript clothing. In terms of the avatar, who is representing a PwD the following attributed were mentioned: confused, unkempt, clothing that matches the age, friendly, well-groomed, depicted in different scenarios, should express appreciation for the care

# 3.6 IMPLICATIONS

The following table provide an overview on the identified issues and describes suggestions for improvement

Table 4: Implications 2nd Lab Trial

Service/functionality	Issue	Description	Implications	
Search for general information	Information ar- chitecture	Lack of user feedback in terms of articles read	mark articles when read	
		Filter options: difficulties to recognize different content elements, difficulties to filter results (users are rather used to select a button to filter results than deselect)	Allow users to select rather than deselect to filter results	
		Lack of paragraphs impeded to easily read the articles	Provide paragraphs, headings, or highlight important terms to make it easier for users to retrieve the most important information	
Search for specific content	Navigation	Difficulties to recognize that search results are displayed while typing (tried to confirm the term via the "enterbutton") — bar with filter elements is distracting	Relocate bar with filter elements to allow users to easily recognize the search results	
		Order of articles is not clear – alphabetical?	Provide a logic to the order of the articles (e.g., alphabetical)	
		Not all key words allow to retrieve results	Provide enough key words to allow users to retrieve adequate results	
		cult to read the articles and to identify most important	Provide a structure to the articles (e.g., use paragraphs, highlight most important content or tips)	
		information	Allow to mark articles / parts of content to quickly find them again if needed	

	Content	The links that are provided are considered partly useful	Provide more concrete links that address the topic of the article (avoid providing always the same links)	
	Content	Need for concrete tips (e.g., how to behave in certain situations)	Tips need to be revised	
Quick help	Visibility	Tags are difficult to read (white font, grey background)	change colours of the tags to increase readability	
		Not all participants immediately found the quick and help function	Provide a more prominent button?	
	Usability / meaning of tags	Meaning of tags is not clear (e.g., when searching for aggression other results are displayed)	Show only results that are relevant (e.g., when typing in "aggression")	
		Wording to search for tips does not fit the tags, E.g., users won't use memory loss but forgetfulness or would paraphrase—e.g., does not remember	Provide sufficient key words to guarantee that users receive adequate search results	
	Navigation	Users did hardly understand that they needed to click on the tip to easily go through all the tips	Automatically show the first pop-up	
Avatar lecture	Navigation	Difficulties to understand how to interact with the avatar - users sometimes tried to start the lecture by clicking on the text field on the bottom half of the screen not the green button	Separate menu to select the main topics from interaction modalities (providing an answer to the avatar)	
		The green icon (dialogue balloon) is used to give an answer to the avatar and to retrieve response options — navigation and interaction with the avatar is mixed up		
		Difficulties to retrieve the main topics (work, leisure, etc.)	See above	
		Difficulties to go back to the main menu (same buttons as in the interaction with the avatar are used	See above	

		No possibility to pause the lecture		Allow to pause the lecture	
		No information about duration of lecture	Provid	le feedback to the user about duration of the lecture	
	Design	Dissatisfaction about the design of the avatars – voice and gestures do not fit together, overall appearance does not fit the situation (avatar, who provides the lecture appears unkempt, not trustworthy)	Redesi	Provide more natural movements that fit the given situation  Consider appropriate appearance of the avatar (e.g., avoid that the avatar, who provides a lecture looks unkempt)  Provide appropriate clothing	
Avatar role play	Navigation	In terms of the navigation the same navigation problems occurred – see above			

# 4 SUMMARY

The iterative evaluation of the SUCCESS prototype focused on an active involvement of potential end users (formal as well as informal care givers) in an early stage of the development process. It particularly supported us in the early detection of a variety usability as well as accessibility problems. Thereby, especially, the overall information architecture and navigation could be improved. Moreover, we could gain valuable feedback regarding the development and revision of content for the SUCCESS app. Based on the results, implications were generated and discussed with the development team and the prototype was further developed, building a sound basis for the upcoming field trials (see also D5.1 and D5.2).

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# APPENDIX A 1<sup>ST</sup> USER STUDY IN THE LABORATORY

Detailed description of tasks, content and provided screens

### Task 1: Get guidance for a specific situation – training for a specific situation (based on use case 3)

**Scenario** (formal care giver): The last few months you have been taking care of an older lady with dementia. Although you have knowledge and experience with dementia you sometimes feel over challenged, because the lady often over-reacts to minor things and starts hitting and cursing. Moreover, you are often not sure how you should behave in terms of memory loss. The app provides guidance how you can deal with such situations.

**Scenario** (informal care giver): A few months ago, your mother was diagnosed with dementia. Although you have knowledge and experience with dementia you sometimes feel overcharged, because she often over-reacts on minor things and starts hitting and cursing. Moreover, you are often not sure how you should behave in terms of memory loss. The app provides guidance how you can deal with such situations.

#### Task:

- → Please search for *respectively two suggestions* on how you could cope with somebody, who starts *hitting* and *cursing* and find tips in terms of *memory loss*.
- → Afterwards, return to the home screen

#### **Questions:**

- → How easily could you find the required information? / Did you miss information? (explicitly ask participants how they experienced the navigation structure)
- → To what extent is the information useful for you? (ask why / why not)
- → Do you have any suggestions for improvement?

### **Required Screens:**

- 1. Home Screen (user selects "get guidance for specific situations")
- 2. Screens for hitting
  - a. Submenu: physical aggressive; physical non-aggressive; verbal aggressive; verbal non-aggressive (user selects physical aggression)
  - b. Submenu: Aggression/Anger; Physical sexual advances (users selects aggression/anger)
  - c. Results: Biting, kicking, pushing, hitting (user selects hitting and receives more information about hitting; afterwards return to the home screen)
- 3. Screens for cursing
  - a. Submenu: physical aggressive; physical non-aggressive; verbal aggressive; verbal non-aggressive (user selects verbal aggression)
  - b. Submenu: verbal sexual advances, suspicion and delusion, aggression/anger, false accusation (user selects aggression/anger)

- c. Results: screaming, cursing (user selects cursing and receives more information about cursing; afterwards return to the home screen)
- 4. Screens for memory loss:
  - a. Submenu: physical aggressive; physical non-aggressive; verbal aggressive; verbal non-aggressive (user selects verbal/non-aggressive)
  - Results: Depression/Apathy, repetitive sentences/questions, memory loss, hallucinations, failure to recognize people (user selects memory loss and receives more information about memory loss; afterwards return to the home screen)
- 5. Reward is provided
- 6. Home screen

#### Content:

### Physical aggressive - hitting

Some people can feel aggressive at times because of their dementia. This may shock you and you may find it difficult to deal with. However, it is important to remember that aggressive behaviour is caused by the disease rather than the person with dementia. The person may become aggressive because s/he is frustrated at not being able to do things s/he used to be able to do. Or s/he may misunderstand what is going on. Sometimes someone with dementia may over-react to something very minor. The part of the brain which would normally control the reaction may be damaged.

### Advice 1

To remain in control of the situation, it is important to try to stay calm. This will probably not be an easy task, particularly if the person with dementia trying to hit you. It might help to bear in mind that the person's actions are caused by the disease and not meant personally against you. Try to give the person plenty of space and time.

## Advice 2

Try to find out what is causing the behaviour. Think about what happened right before the reaction that may have triggered the behaviour. Is the person experiencing physical pain? Is the person overstimulated by loud noises, an overactive environment or physical clutter? Did you say something that was possible to misunderstand?

### <u>Verbal aggressive – cursing</u>

Verbal abuse is more common than physical aggression. The person may shout, curse or make accusations or threats. The person may become verbal aggressive because s/he is frustrated at not being able to do things s/he used to be able to do. Or s/he may misunderstand what is going on. This can be very upsetting and quite a shock for you. You will probably find it difficult to remain calm and not take the anger personally. You might feel hurt and sad at what seems to be a change in the person's character. It is important to try to remember that the angry outburst is most probably a consequence of the disease.

### Advice 1

Try to distract their attention if they remain angry. For example, you could suggest having a drink together, going somewhere or doing something that the person likes.

#### Advice 2

The person with dementia might misinterpret helpful instructions, prompts or explanations, even if what you say might not sound wrong to anyone else. You might occasionally sound patronising or bossy without realising it. Try phrasing what you say differently. For example, instead of saying, "Now put your coat on", you could say, "Here's your coat. Let me help you put it on"

#### **Memory loss**

Memory loss is one of the most common symptoms. It is often the first sign which leads people to suspect that there is a problem and seek medical advice. However, it is important to realize that people tend to lose their memory gradually rather than all at once. The person with dementia may become more confused and 'lost' or disorientated. The person may forget basic facts such as who other people are, where they are and what year it is. S/he may confuse the past with the present.

#### Advice 1

It is often unnecessary to draw attention to mistakes. For example, when you are talking to someone with dementia, they may use an inappropriate word because they cannot remember the correct one. You may feel inclined to correct the person or even do so automatically. However, if you have understood what they were trying to say, this is unnecessary and likely to make them feel uneasy, embarrassed or annoyed.

## **Advice 2**

In the early stages of dementia, memory aids such as lists, diaries, clocks and clear, written instructions can help jog the person's memory if they are willing and able to make use of them. As the dementia progresses, the person may become less able to understand what the aids are for.

#### Task 2: Guidance for specific situation – in situ guidance (based on use case 2)

**Scenario 2a (formal care giver)**: You just arrived at your client's home. The lady is upset and insists to go shopping. You do not have that much time this day. You start explaining that this won't be possible this day and while you are talking the lady becomes starts cursing and hitting at you. You feel slightly overstrained in this situation and decide to search for a quick advice via the app.

**Scenario 2a (informal care giver)**: You just arrived at your mother's home. She is upset and insists to go shopping. You do not have that much time this day. You start explaining that this won't be possible this day and while you are talking, your mother starts cursing and hitting at you. You feel slightly overstrained in this situation and decide to search for a quick advice via the app.

### Task 2a:

- → Look up some *quick advice for cursing and hitting* (the first advice that is provided is not useful for you but can make use of the second quick advice).
- → Afterwards you will be automatically redirected to the home screen

**Scenario 2b (formal and informal care giver):** After you are at home again you open your app. You receive some follow-up information regarding the in-situ advice you received that day.

#### Task 2b:

- → Please *rate the usefulness of the advice* (very useful) and find out how many experience points you earned this day.
- → Afterwards return to the home screen

#### Questions:

- → How easily could you find the required situation?
- → Could you find out how many experience points you received?
- → What are your thoughts towards the visualization of the quick info was it useful? (if yes/no why was it useful/not useful?)
- → Can you imagine using this functionality in a case where you would need quick advice?
- → Do you have any suggestion for improvement?

### Required Screens (Task 2a)

- 1. Home Screen (user starts "in situ help")
- 2. Free text form field is displayed (users are asked to indicate which wording they would choose and will be directed then to a quick info)
- 3. Quick info is displayed (user reads quick info and system asks if the info was useful user indicates no)
- 4. Next quick info is displayed (user reads the quick info and indicates that it is useful)
- 5. Automatically redirect to the home screen

### Required Screens (Task 2b)

- 1. Home Screen with question (e.g., pop up) to rate the usefulness (user rates "very useful")
- 2. Home screen with information regarding experience points earned (pop up?) (user receives experience points)
- 3. Home screen visualizing the experience points earned (user sees experience points and returns to the home screen)
- 4. Home screen

## In-situ guidance hitting

- 1. Remain calm and reassuring
- 2. Try to identify immediate cause

#### In-situ guidance cursing

- 1. Try to distract the person
- 2. Rephrase what you said

### Task 3: Train your communication strategies (based on use case 4):

**Scenario (formal and informal care giver):** The app does not only provide information about possible behavior in specific situations but allows you to train and expand your skills. You have already read some useful information about cursing and hitting, so the app unlocks a training challenge for you. You are curious and since you would like to strengthen your knowledge, you decide to accept the challenge.

#### Task:

- → Please strengthen your communication skills.
- → Afterwards return to the home screen

#### **Questions:**

- → How easily could you find the required information?
- → How useful did you experience the "dialogue" with the avatar?
- → Can you imagine training you skills in a virtual dialogue with an avatar?
- → Do you have any suggestions for improvement?

#### **Required screens:**

- 1. Home Screen (user selects train communication strategies)
- Screen showing the challenge provided for the user (user accepts challenge)
- 3. 3-4 screens showing the avatar with a dialogue balloon (user goes through the interactive dialogue and answers the questions)
- 4. Screen that shows that the user has finished the challenge and points that have been earned (user returns to the home screen).
- 5. Home screen (user returns to the home screen)

#### Questions aggressive behavior (hitting/cursing)

Which aggressive behavior is most common?

- a) Physical aggressive behavior
- b) Verbal aggressive behavior (correct)

If the person with dementia is getting aggressive, you should try to

- a) Keep calm (correct)
- b) Restrain the person

If the person over-reacts when you say something, it's probably smart to try to

- a) Explain that they are mistaken
- b) Rephrase what you said (correct)

## Task 4: Tips for meaningful activities / gamification (based on use case 5)

**Scenario (formal and informal care giver):** Offering activities to people with dementia can help to create meaning in their lives. Imagine that you want to provide such activities to the person you are caring for.

#### Task:

- → Explore the app for suitable suggestions for reminders of the past
- → Read more about one concrete activity you could carry out (reminders of the past)

#### **Questions:**

- → How easily could you find the required information?
- → How helpful / useful were the suggestions?
- → Would you use such a function in your day-to-day care routine?
- → What do you think about the reward provided by the app? (Do you consider the reward to be motivating?)
- → Do you have any suggestion for improvement?

#### Required screens / content:

- 1. Home Screen with the main categories of the app (user selects meaningful activities)
- 2. Subcategories are visualized (user selects an area reminders of the past)
- 3. Possible activities for a specific area are displayed (user selects an activity and reads more about it)
- 4. Screen with more information about one certain activity (user reads the information and indicates somehow that s/he has read the information)
- 5. After reading a suitable information: screen displaying a reward (user returns afterwards to the home screen)
- 6. Home screen

#### Subcategories

# 1. Work (examples)

- Adjust the task they used to do
- Fold clothes
- Tighten or loosen screws
- Sweep floors
- Stock supplies

### 2. Self-care (examples)

- Sing a song the person likes
- Hand massage
- Back rub

### 3. Leisure (examples)

Reminders of the past

- Look at photo albums
- Look through scrapbook
- Visit familiar places from their childhood/adult life
- Look at old movies

### Exercise/ staying active

- Take a walk
- Go for a swim
- Do yoga

#### Animals

- Visit a farm
- Pet a dog/ cat

### Arts/ Handcrafts

- Make a scrapbook by cutting and pasting colorful pictures from old magazines of things
  that are meaningful or pleasurable for the person with dementia. Let the person with dementia select each picture or word to be included in his/her book
- Drawing/ painting
- Making collages
- Photography

### Music

- Listen to music
- Play music

### Other activities

- Bake together
- Play card

### 4. Rest and restoration

- Quiet time in a room with music
- Spending time in nature

### Task 5 Emotional Support / Gamification (based on use case 7)

**Scenario (formal and informal care giver):** Imagine you've had a hard day. During care, you faced some incriminating situations. You wish for a possibility to reflect upon your feelings to take care of yourself.

#### Task:

- → Explore, in what way the app provides support for reflection (after the user has found the area for self-reflection indicate that s/he should find out more about "rejuvenation")
- → Return to the home screen

#### Questions:

- → Was the information easy to find?
- → Do you think a self-assessment (or similar wording) like in the app can support you in a comparable, real situation?
- → Would you do something different? If so, what would you change?

### Required screens:

- 1. Home screen with the main categories of the app (user selects the category emotional support)
- 2. New screen with sub-menu reflection/avoid self-stigma and organize your day activities
- 3. Several consecutive screens with questions for self-assessment/reflection (users will answer questions)
  - o Turn card: Reflection, Resilience and Self-Compassion as a Caregiver (user selects rejuvenation)
  - Turn card: Rejuvenation (users select 2-3 self-care practices for the purpose of the study the self-care practices are automatically selected) Participants are asked to indicate if they missed any self-care practices
  - Screen: "self-care practices": Possibility to rate each of the selected self-care practices on a scale from 1 to 10, asking how often they engage in such activities (user selects a value - for the purpose of the study the rating is preselected) Information for the participants: based on their answers for self-care practices participants will receive suggestions to engage in activities.
  - Screen: Self-Compassion: Screen that asks participants how they would respond to a friend who really messed up (participants have the possibility to indicate how they would respond to a friend – text field – for the purpose of the study text is already filled in – users are asked what they would answer)
  - Screen: Self Compassion: Screen that asks participants how they would respond to themselves if they messed up (user indicates text – for the purpose of the study text is already filled in)
  - Screen: Did you notice a difference? If so, ask yourself why: Why not trying to treat yourself like a good friend and see what happens?
- 4. Screen that allows users to end the refection and to return to the home screen