AAL Programme

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

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# SUCCESS

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| DELIVERABLE DESCRIPTION | Report on the user trials and evaluation. This report describes the results of the two field studies, carried out in T5.2. The first study focused more on a qualitative evaluation including overall 18 caregivers. The second study addressed in sum 68 informal and caregivers who used the system for 6 months. Quantitative measures were applied to assess the impact of SUCCESS on the defined KPIs. |
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# ABBREVIATIONS

| ABBREVIATIONS | DESCRIPTION |
|---|---|
| AAL | Active and Assisted Living |
| AAL CMU | AAL Central Management Unit |
| PwD | Person with dementia |
| TP | Test person |

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## AAL PROJECT SUCCESS

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

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

# EXECUTIVE SUMMARY

Based on the outcome of the two user studies in the lab, carried out in Austria and Romania (see D2.3) the identified user experience and usability issues were addressed, and the Avatar training was further developed so that users had access to the trainings (Role Play and Lecture) via the app. To evaluate SUCCESS with users in a real-life context, two field studies were carried out, involving formal as well as informal caregivers.

The 1st field trial was conducted in May and June 2018. This study, involving in total 20 informal and formal caregivers in Austria and Romania, had a qualitative focus and aimed at understanding users' experience, acceptance and satisfaction when interacting with the SUCCESS system. Moreover, feedback on the avatar was collected and a first analysis on what extent the services caused changes in care (for formal as well as informal caregivers) was performed. Finally, feedback on the business models was obtained and the instruments that have been prepared for the 2nd field trial (burden of care, quality of life for care givers, behavioural problems of PwD etc.) were tested.

The analysis of the results showed very encouraging results as well as suggestions for improvement of the design and functionality of the app. Related to user experience, acceptance and satisfaction, the participants of the 1st field trial were satisfied with the app. Favourite functions and most positive experiences with the app included the articles, the videos, the quick help and the guided meditation. The most negative experiences of the participants included frequent crashes of the app and other technical aspects as well as the negative appearance of the avatars. Related to potential changes in care, the 1st field trial showed, that the app can have a positive effect on the interaction with the PwD and the well-being of the caregiver. The content of the app especially helped informal caregivers to deal with everyday challenges such as aggression and to better use their own resources.

The 2nd field trial was conducted between May 2019 and January 2020. This trial followed a quantitative pre-post research design, complemented with qualitative elements. In total 68 participants – 31 in Austria and 37 in Romania – were involved to the trials, thereof 38 informal and 30 formal caregivers. Quantitative and qualitative data was collected at baseline, after one month, three months and six months. The defined outcomes included burden with care, caregiver satisfaction, behavioural and psychological symptoms of dementia of the PwD, self-efficacy of the caregiver, care-related knowledge, and the user experience of the SUCCESS app. In addition, technology acceptance, changes in care and socio-economic aspects were assessed.

Results of the 2nd field trial showed that most caregivers benefit from the information and training offer provided by SUCCESS. The analysis of the quantitative data showed a statistically significant increase of caregivers' dementia-related knowledge throughout the study. Caregivers perceived a decrease in the severity (not significant) and distress (significant) related to behavioural and psychological symptoms of dementia of the person cared for. In addition, the results also indicate a reduction of the burden related to the care responsibility as well as an increased satisfaction and self-efficacy of the caregivers (not significant). The assessment of the user experience of the SUCCESS app confirmed a high pragmatic and hedonic quality of the system. Qualitative results underline these positive results: Many participants stated that they value having a trustworthy tool to reassure themselves of their own behaviour and as a source for alternative interaction strategies and meaningful activities. The results also underpinned family caregivers and informal caregivers without much dementia-related experience as core target group and confirmed their willingness to pay based on a subscription model with monthly or annual payments.

# 1 ABOUT THIS DOCUMENT

## 1.1 ROLE OF THE DELIVERABLE

This deliverable describes the results of the two field studies, carried out in *T5.2 Field study preparation and execution*. The first study focuses more on a qualitative evaluation including overall 20 PwD. The second study addresses in sum 60 care givers and 60 PwD who use the system for 6 months. More quantitative measures are to be applied.

This document summarises the results of *T5.3 User-benefit analysis* and *T5.4 Socio-economic impact analysis* (initially planned as separate deliverable *D5.3 Socio-economic evaluation report*; partly included to *D6.6 Final business plan*).

## 1.2 RELATIONSHIP TO OTHER SUCCESS DELIVERABLES

The deliverable is related to the following SUCCESS deliverables:

| DELIVERABLE | RELATION |
|---|---|
| D5.1 | Trial and Training concept: This document describes the overall setup of the two field trials, i.e., implementation plan and research methodology. |
| D2.3 | Low and High-Fidelity Prototype Evaluation Report: The results from the evaluations in the laboratory built the basis for the further development of the app. |

# 2 FIRST FIELD TRIAL

This section describes the results from the first field trials that took place for a duration of six weeks (21st/22nd of May until the 29th/30th of June 2018) in Austria and Romania, involving overall 17 potential end users (formal as well as informal care givers).

The following objectives of the qualitative trial were addressed.

a) To understand the user experience, acceptance and satisfaction
b) To obtain feedback on the interaction with the avatar
c) To obtain feedback on the SUCCESS draft business models
d) To explore changes in care
e) To analyse frequency and patterns of use for the SUCCESS App
f) To test/pilot a set of quantitative instruments which will be used in the quantitative trial to assess the burden of care and quality of life for caregivers and the stage of disease and the behavioural problems of PwD

## 2.1 SAMPLE DESCRIPTION

Austria:

The Austrian sample consisted of eight participants, four women and four men, who attended this trial either as formal or informal caregivers.

**Formal caregivers:** Half of the study participants were involved in the professional care of people with dementia, three of the test users themselves have been professionally trained caregivers for several years. One of the participants of the formal care runs a domestic 24 hours care. S/he has not absolved a professional education within the care sector, however has gained experience in caring for persons with dementia, throughout the last years.

**Informal caregivers:** This group of users consisted of relatives or friends involved in the care of PwD. Two participants were main care givers and lived in the same house as the PwD. Even if they did not have any professional training in the field of dementia care, they have already acquired a broad knowledge due to the long-term and continuous nursing task and were well connected with discussion- and self-help groups. The spatial and emotional proximity to the PwD also leads to a high temporal and psychological burden, as well as inescapability of the examination of the topic.

Another two participants of the group of informal caregivers were not main care givers and did not live in the same house as PwD. Due to the technical conditions of the caregiver's smartphones, only one of them was able to transmit and evaluate usage data.

Table 1: Demographic Data Participants Austria

| ID (Formal/ Informal) | Gender | Age | Highest completed education | Occupation | Family status (multiple choice) |
|---|---|---|---|---|---|
| TP 1 (Formal) | male | 50 | Professional School / Apprenticeship | full-time employed | married |
| TP2 (Formal) | male | 47 | Professional School / Apprenticeship | full-time employed | widowed |
| TP 3 (Informal) | female | 72 | Professional School / | unemployed | widowed |

| | | | | | |
|---|---|---|---|---|---|
| | | | Apprenticeship | | |
| TP 4 (Formal) | female | 24 | Other: Certificate for nursing care | full-time employed | living in a partnership |
| TP 5 (Formal) | female | 37 | General qualification for university entrance | part-time employed | divorced |
| TP 6 (Informal) | male | 70 | General qualification for university entrance | unemployed | married |
| TP 7 (Informal) | female | 64 | General qualification for university entrance | unemployed | married |
| TP 8 (Informal) | male | 68 | General qualification for university entrance | unemployed | married |

<u>Romania:</u>

For Romania, a total of 10 users were recruited for the study, whereby, the majority of these were informal caregivers (i.e., nine out of ten). One of the participants dropped out of the trial after the initial interview, because s/he travelled to a foreign country). Hence, overall nine users were included in the analysis.

**Formal caregiver:** the formal caregiver included in the qualitative trial provides home care for people with dementia for over ten years. She is 54 years old, trained as a psychologist and provides weekly two-hours cognitive training sessions and occupational therapy for people suffering from dementia.

**Informal caregivers:** The group of users consisted of relatives of PwD (five of them are children, one son-in-law, two are partners and one niece). Seven of the participants live in the same house with the PwD and eight of them are the main caregiver. One of the informal caregivers is medical doctor by background. This participant particularly gave feedback within the evaluation on the novelty of the information.

Table 2: Demographic Data Participants Romania

| ID (Formal/ Informal) | Gender | Age | Highest completed education | Occupation | Family status (multiple choice) |
|---|---|---|---|---|---|
| TP 9 (Formal) | female | 54 | University degree | full-time employed | divorced |
| TP10 (Informal) | female | 56 | Master degree | unemployed | divorced |
| TP11 (Informal) | male | 51 | PhD | full-time employed | married |
| TP 12 (Informal) | female | 50 | Master Degree | full-time employed | Single |
| TP 13 (Informal) | female | 49 | PhD | full-time employed | married |
| TP 14 (Informal) | female | 64 | Elementary school | unemployed | married |

| | | | | | |
|---|---|---|---|---|---|
| TP 15 (Informal) | female | 32 | General qualification for university entrance | full-time employed | single |
| TP 16 (Informal) | male | 75 | General qualification for university entrance | unemployed | married |
| TP 17 (Informal) | female | 36 | University degree | maternity leave | married |

## 2.2 RESULTS

In the following chapter, the main results are described, structured according to our central objectives.

### 2.2.1 USAGE TIME AND USER EXPERIENCE

#### 2.2.1.1 USAGE TIME

Austria

The exact number of days the participants were using the app ranges from 3 to 21 days. During this period, participants spent between 16 minutes and 5.75 hours in using the app (total time of use). It is noticeable that, on average, informal caregivers spent much more time on using the app than formal caregivers. The two main caregivers used the app most intensively, on 14 / 21 different days at approx. 11 / 16 minutes per day and consulted content from the app 36 / 75 times.

Regarding the usage time, there is no clear difference between the two groups of formal and informal caregivers. The average total usage time of all participants was 01:49 hours, varying from a minimum of 00:16 minutes to a maximum of 05:43 hours (see Table 3).

Table 3: Usage Time

| ID (Formal/ Informal) | Usage days | time/usage day | Total usage time | Contents viewed |
|---|---|---|---|---|
| TP 1 (Formal) | 8 | 00:16:02 | 02:08:17 | 49 |
| TP 2 (Formal) | 4 | 00:04:06 | 00:16:24 | 12 |
| TP 3 (Informal) | 4 | 00:13:28 | 00:53:52 | 11 |
| TP 4 (Formal) | 5 | 00:09:34 | 00:47:50 | 19 |
| TP 5 (Formal) | 3 | 00:06:11 | 00:18:33 | 5 |
| TP 6 (Informal) | 14 | 00:11:02 | 02:34:31 | 36 |
| TP 7 (Informal) | 21 | 00:16:36 | 05:43:51 | 75 |
| Average | 8,4 | 00:11:00 | 1:49:03 | 29,6 |

All test users, who are qualified as professional caregivers, generally evaluated the app as positive, although they could hardly gain any new information for themselves and therefore rather recommend it to caregiving relatives or inexperienced caregivers. The experienced caregivers reported that the usage of the app did not cause any changes in daily care. They pointed out that they have already established fixed routines on the basis of long-term experience.

The article about "hiding and losing objects" has been by far the most read article. Also popular among the participants were articles about physical aggression, false accusations, verbal aggression, repetitive sentence questions and physical sexual advances.

Romania:

Self-reported usage patterns ranged from once during the trial period to every few days. Some participants reported that messages sent from the app prompted them to go back to the app, others would go back for the guided meditation or just to re-read some of the articles when more time became available. Due to difficulties with retrieving the usage data, a quantitative analysis of usage times is not available for Romania.

#### 2.2.1.2 USER EXPERIENCE, ACCEPTANCE AND SATISFACTION

Austria:

Overall, all test users of the first field trial were satisfied with the idea and content of the app, which can be illustrated by the following statement of a participant: *"It is a great app where I could read well prepared contents and concisely presented information. I think it's very good for caregiving relatives. I also like the internet links where you can find some more information." (TP5)*

Linguistic errors, system crashes and the poor design of the avatars were considered critical by all test persons, who indicated that it sometimes affected their motivation to continue using the app. Five participants mention technical problems (e.g., the app was very slow or often crashed) as the most negative experience during the field trial. In addition, all participants identified a need for improvement in the design of the avatars. The strong negative criticism of the participants indicates that the design of the avatars is not yet appropriate. All test users agree that the avatars should be more natural, friendly looking and need to have a more positive appearance.

Apart from that, all eight participants were satisfied with the app and the provided information and would like to be contacted for follow-up studies. Two participants explicitly asked how the study is going to proceed from that point. One participant of the informal caregivers group mentioned several times during the final interview that she would like to keep the app on her private mobile phone to be able to continue supporting the PwD: *"This app is great! It's such a pity I won't have it anymore! I'd like to go into further details, because this is so incredibly great!" (TP3)*

All participants perceived the information provided by the app as useful; four participants stated that the articles are even the most positive experience or favourite function in the entire app. Two other participants were especially positive about the guided meditation.

Three participants mention Quick Help as their favourite function, indicating that they appreciated being quickly directed from a keyword to the corresponding article. Three other participants of the study were not even able to find the Quick Help function and consequently did not use it. Hence, the Quick Help seems to be not good visible for all participants. One participant also stated that s/he was not familiar with the term "Quick Help", hence had difficulties to understand the meaning and purpose behind this function.

Apart from that, six of the eight participants agreed that the videos presented in the app are great, demonstrating concrete care situations. One participant also highlighted the usefulness of internet links, providing additional information if required.

For similar apps developed in the future most of the users would expect the possibility to find all important information in an understandable manner from an app that supports them in everyday care work. Due to big differences in previous knowledge, the provided information needs to be more detailed for professional caregivers and sometimes also for informal caregivers, e.g., for relatives and friends who are only partially involved in care activities. This indicates that there is a need to filter content according to the previous knowledge of the care giver and the severity of dementia.

Results with regard to the technical procedure and the design of the navigation elements indicate that there is a need for improvements in order to ensure an intuitive and problem-free use of all functions.

Users would wish for additional content like a quiz for checking already existing knowledge, instructions for reflecting on aggression, tips for memory training, and contents on the topics "Ageing of people with (mild) dementia" and "Younger people with dementia".

Romania:

In Romania, the participants of the first trial also found the SUCCESS app to be useful and the information included valuable. On the "The Usability Metric for User Experience" (UMUX) scale[1], the users evaluated that the app meets their requirement, the average of 5,13 being reflective of the expressed need of the users for more articles (all items were measured on a 7-point scale, 1 = strongly disagree and 7 = strongly agree). Participants evaluated the SUCCESS app to be easy to use and, overall, not a frustrating experience. However, the frequent crash of the app determined users to evaluate the app as slightly time consuming (average 3,13).

Table 4: UMUX results

| Items UMUX | TP9 | TP10 | TP11 | TP12 | TP13 | TP14 | TP15 | TP16 | Avr |
|---|---|---|---|---|---|---|---|---|---|
| The capabilities of SUCCESS met my requirement | 2 | 7 | 5 | 3 | 7 | 7 | 3 | 7 | 5,13 |
| Using SUCCESS is a frustrating experience | 1 | 1 | 3 | 3 | 1 | 1 | 2 | 1 | 1,63 |
| SUCCESS is easy to use | 7 | 5 | 4 | 5 | 7 | 7 | 7 | 6 | 6,00 |
| I have to spend too much time correcting the things with SUCCESS | 1 | 2 | 2 | 5 | 6 | 1 | 3 | 5 | 3,13 |
| Total score (%) | 79.1 | 87.5 | 70.8 | 50.0 | 95.8 | 100.0 | 70.8 | 70.8 | 78.1 |

Most of the users' relatives included in the qualitative trial are in the early stages of the disease, which also meant that participants had a limited level of knowledge in the area of behavioural and psychological symptoms and their management, which is illustrated by the following statement: *"My mother is at the beginning of the disease so first I read the articles about behaviours I could recognise and then read the rest of the article to learn more about situations that might appear in the future"* (TP17). The content included was thus found to be new and relevant by most of the participants (i.e., seven out of ten; an informal caregiver with over five years of experience caring

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[1] The UMUX is a short scale, targeted towards the assessment of usability by means of measuring effectiveness, efficiency, and satisfaction.

for a PwD, the informal caregiver trained as MD and the formal caregiver were exceptions). For the formal caregiver, the information included in the app was not new but she appreciated that most of the caregivers would find the app very useful if they would be introduced to it soon after the diagnostic of their relative.

The written articles were used and highly appreciated by all participants. However, it was indicated that improvements are required with regard to the structure of the test and small linguistic or punctuation errors, which have been found to be disturbing. In four out of nine cases, malfunctions have been encountered when trying to use the text to speech function for the written articles.

The video for guided meditation was also appreciated by some of the participants (seven participants said they tried it; two reported daily usage).

The Quick help function was unfrequently used or not used at all, reasons for this being either the fact that participants could not identify the button as a different function of the app or they did not understand how it actually works.

The reported usage and satisfaction for the avatar-based sections (i.e., lectures, role-plays and the diary) were less uniform. For some of the participants (almost half of them) these sections have malfunctioned from the beginning (e.g., the avatar was not working at all or was playing very fast) or started to malfunction very soon after installation (rest of the participants). For two participants the role plays included were qualified as not relevant (PwD they cared for do not show the behavioural or psychological problems targeted). All participants reported frequent app crashes when trying to use avatar-based sections or very high response times. In addition to technical issues, aspects related to how the avatar looks and interacts have also been highlighted by the participants (for details see next sections).

Overall, the test users of the first field trial were satisfied with the app. Favorite functions and most positive experiences with the app include the articles, the videos, the quick help and the guided meditation. The most negative experiences of the participants include the frequent crashes of the app and other technical aspects as well as the negative appearance of the avatars. Apart from that, everyone is interested in being contacted for follow-up studies.

#### 2.2.1.2.1 Interaction with the Avatar

Austria

**Results from the BIG 5:** Already during the trial, negative feedback regarding the avatar design (for an example of the avatar design see Annex) was reported by the participants during the telephone interviews. The final interviews therefore asked again to what extent the avatar is considered as "appropriate" for the interaction in the role play.

During the final interviews, the participants were asked to think of the PwD they were responsible for and to evaluate the following statements regarding the extent to which they applied to the PwD. Afterwards they received two versions of the BFI-10[2] for the evaluation of the BIG5 dimensions, assessing personality traits.

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[2] The BFI-10 (Rammstedt & John, 2007) is an abbreviated version of the well-established BFI (John et al., 1991), con-

In addition to the answer alternatives of the given five-level Likert scale, a further answer option "I cannot estimate" has been added. It is noticeable that especially the avatar could not be evaluated for some items. TP7 could not make an evaluation regarding the imaginative power of the PwD, because according to TP7 the PwD has never been very imaginative but has now hallucinations due to dementia. If no evaluation was made for one item, the value on the dimension was only calculated by the answer to the other item. In one case, no evaluation could be given for both items.

Comparing the assessment of the PwD and that of the avatars, the participants gave varying evaluations for both. Furthermore, there is a trend among the participants that the PwD and the Avatar have similar scores for each dimension (except of TP3 and TP6). However, this could also be the result of the same questionnaire being used twice.

**Experiences when interacting with the avatar:** A picture of the avatar that was used during the role play was presented to the participants. Guided by the request “I would like to ask you to look at this avatar and imagine the life of this person. Please tell me about what you think about this person’s life, what does it look like, what does the person like to do…”, the participants were asked to talk about their impression.

The avatar did not encourage the participants to imaginative thoughts. They described the appearance of the avatar as worn out, unappealing, scruffy, boyish, with empty gaze and marked by life. All test users described the avatar as inappropriate, very unnatural, unfriendly and in need of improvement. One participant said about the female avatar: *“Strange… the woman looks like the film character Jaws from the movie 007.” (TP6)*

Besides that, users of the app characterized the avatar as aggressive, not tolerating contradictions, having good manual skills, very strict, imperiously, power addicted, not satisfied with the situation and rejecting other people.

The test users described the emotions of the avatar as depressive, strict, frustrated, without any feelings, stressed, sad, radiating negative emotions, suffering, not satisfied with oneself, grumpy and with grumpy facial expression. One participant stated: *“This woman is a disaster! The look, the facial expression - I would prefer not to have anything to do with such a person! Not pedagogically suitable!” (TP2)*

When the participants imagined the life of the avatar, they assumed the avatar had children, smoked (skin of a smoker), used to be sporty (athletic body), had a tough life, or was formerly successful in the profession. One participant said about the female avatar that she knew that she could no longer do everything.

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sisting of 10 items. It assesses the Big Five by two items per dimension, one coded in the positive and one in the negative direction of the scale.

Romania

**Results from the BIG 5**: In Romania, eight participants provided answers for the 10 items of the Big Five inventory (BFI-10) for the avatar and six for the PwD they are caring for. Three of the participants have assessed the male version of the avatar and the remaining five have evaluated the female version. In all eight cases, the gender of the PwD the users are caring for is the same as the gender of the avatar they evaluated.

The BFI-10 scale has two items each for the five personality dimensions: Conscientiousness, Neuroticism, Agreeableness, Openness, Extraversion. While the number of participants is rather small for definite conclusions, the results indicate a tendency to evaluate the avatar lower than both the PwD and the normative values provided by Rammstedt (2007) on Agreeableness, Openness and Extraversion. These results are supported by answers to question referring to the experiences users had when interacting with the avatar (see Table 5 and Table 6).

Table 5: Scores BFI-10 for the Avatar (*N* = 8)

| **Dimension** | ***M*** | ***SD*** | ***M* (B. Rammstedt, 2007 *N* = 2567)** | ***SD* (B. Rammstedt, 2007 *N* = 2567)** |
|---|---|---|---|---|
| Conscientiousness | 4.06 | 1.32 | 4.10 | .69 |
| Neuroticism | 3.56 | 1.49 | 3.49 | .85 |
| Agreeableness | 2.81 | 1.3 | 3.20 | .83 |
| Openness | 2.5 | 1.62 | 3.41 | .88 |
| Extraversion | 2.43 | 1.15 | 3.24 | .88 |
| Mean | 3.07 | 0.71 | 3.49 | .83 |

Table 6: Scores BFI-10 for the PwD (*N* = 6)

| **Dimension** | ***M*** | ***SD*** | ***M* (B. Rammstedt, 2007 *N* = 2567)** | ***SD* (B. Rammstedt, 2007 *N* = 2567)** |
|---|---|---|---|---|
| Neuroticism | 3.7 | 1.16 | 3.49 | .85 |
| Conscientiousness | 3.5 | 1.94 | 4.10 | .69 |
| Extraversion | 3.0 | 1.26 | 3.24 | .88 |
| Agreeableness | 3.0 | 1.37 | 3.20 | .83 |
| Openness | 2.1 | 1.20 | 3.41 | .88 |
| Mean | 3.06 | 0.61 | 3.49 | .83 |

These results are supported by answers referring to the experiences users had when interacting with the avatar.

**Experiences when interacting with the avatar:** Overall the avatar was perceived as strange (“creepy”) by some participants and the voice of the avatar was perceived as being metalic (digital): *“The way he speeks is not very friendly”*. The avatars were also perceives as *“not very intelligent, perhaps due to the harsh features”(TP10)*.

Some participants indicated that the clothes, the hair, and the face of the avatar do not fit the age, i.e., are experienced inapropriate: *“Few of the elderly people dress in active wear; the hair of the avatar is not white and there are no wrinkles on the faces of the avatars”(TP10)*. One participant even commented that the female avatar *“looks like a corner street beggar lady who could use a shower”(TP17)*.

The body of the avatar is perceived as being rather rigid and creates the impression that it is difficult to communicate with; one user mentioned that *"it is disturbing that the avatar is holding his hands on the hips"(TP12)* and some users would prefer to see only the upper part of the avatar. Otherwise, the female avatar was described as an active person, without physical problems but possible inadequate for portraing a person with dementia: *"she has a good posture but not necessary adequate for the situation of the PwD"(TP13)* (i.e. persons, who suffer from dementia might be a bit more frail).

In terms of personality, the avatar was described as *"not very friendly, a though person who dosen't look like he suffers from Dementia. The eyes of the avatar are different from the eyes of a PwD, who seem a bit lost"(TP10)*. Another participant indicated that the avatar *"looks like a clown with a rather hostile attitude (it makes me feel alerted)"(TP12)*. Users also pointed out that the avatar seems to be *"upset all the time"*. For the female avatar, some users also indicated that she seems like a violent person, who is upset and can inspire fear.

Possible jobs the avatar might hold, indicated by the users were: a) for the female avatar: *"She works in a factory, on a production line"(TP12); "She is a tough manager or a very tough teacher" (TP14)*; b) for the male avatar: *"He works in IT or in a corporation; he dosen't look like needing medical care"(TP16); "He is a lonely person who works in an office, perhaps even a management job"; "a person who like to work with his hands, perhaps a a handyman, farmer or carpenter"(TP10).*

For hobbies, the female avatar was perceived as loving sports and walking; also users said that she is *"not very good at cooking or kniting"(TP17).* For the male avatar, hobbies mentioned by users were reading or watching TV.

In general, test users described the avatars as unappealing, aggressive and stressed. All participants agreed, that the avatars are not appropriate for the interaction in the role play. Improvements are required with regard to the appearance and also the behavior (postures, ges-

### 2.2.2 BUSINESS MODELS

Austria

None of the participants had ever downloaded an app on their mobile phones to support them in their daily care routine. Only one user could not imagine paying for an app that supports him/her in maintenance, because s/he already had a lot of previous knowledge. S/he also noted that despite of his/her active search for information and good networking, s/he does not know any app that could be helpful in everyday care. Another participant from professional care could only imagine paying for an app that supports him/her in everyday care if it would provide a wide range of tips on how to behave in different care situations for people with various diseases.

All other participants could imagine paying for an app like SUCCESS. In addition to improved technical usability (e.g., appropriate time required and compatibility with various operating systems), such an app would then have to offer quick and concrete tips to help in specific situations. One participant would like the app to be easier to understand and be offered in different languages.

Most participants do not have a reference point regarding the costs of an app in general but said that they would be willing to pay 2 Euro per month (one participant) or between 5 Euro and 15 Euro per month.

Romania

None of the Romanian participants has previously used a mobile app to support them in their daily care routine, but they indicate they would buy SUCCCESS if proved to be useful. For the price, the participants offered that they would be willing to pay what should be comparable to a similar app or a book (between 1 and 5 Euros a month).

Most of the participants could imagine paying between 2 and 15 Euro per month in Austria and between 1 and 5 Euros per month in Romania for an app like SUCCESS, expecting that the technical problems are resolved, usability is improved and more quick and concrete tips for specific situations are provided.

### 2.2.3 CHANGES IN CARE

Austria

The use of the SUCCESS app had different effects for formal and informal caregivers. Statements of the participants regarding changes in the care situation, care behaviour, care activities, and routines were extracted, thematically structured, and are summarized below.

#### 2.2.3.1 CHANGES IN CARE FOR FORMAL CAREGIVERS

Three out of four formal caregivers stated that they did not experience any changes, as they had already established a firm and successful routine and were consolidated in their nursing activities. However, one participant stated, that the app helped him/her to break out of his/her daily routines.

Accordingly, only a few changes in care for formal care givers have been reported. The topics that were discussed in this context are described below.

**Aggression:** Two participants explained that the app allows to train preventing aggressive behavior in a “safe environment”. One participant reported that the app helped him/her to stay calm while the person s/he was caring for became aggressive.

**Interaction with the PwD:** Since the professional caregivers were already experienced in interacting with people with dementia, the use of the app primarily encouraged them to reflect upon their own behavior and established routines in order to remedy possible carelessness or errors. Apart from that, none of the formal caregivers' interaction with the PwD was affected by the app.

**Caregiver’s life:** Three of the formal caregivers stated that they did not notice any changes in their own life when using the SUCCESS app. However, the person, who runs the 24-hour care indicated that s/he can imagine that the app might have an impact on the caregiver's working life in terms of care relationship, methods, and day-to-day organization. Another participant indicated that there certainly might be changes for employees, who do not work professionally. Only one test user noticed during the trial that s/he remains calmer in specific situations and could better deal with aggressive behavior. In addition, the app helped him/her to break out of the usual routine.

**Selfcare:** Half of the formal caregivers had a very good impression of the self-reflection function and perceived the presented information as sufficient: *“I really like the fact that the caregiver can just lean back and check what is good for me, what is important for me? Can I now use the family's resources? Recognizing these things is very important to the caregiver, simply to look at oneself and not to get lost in the daily stress.” (TP1)*

It is interesting that the other half of the formal caregivers had the opinion that they do not personally need self-reflection or the self-reflection-function, but believe that it can be very helpful for other people: *“I think it's good, I think it's fine, I can imagine it for caregiving relatives. But I personally don't need it.” (TP4)*

One participant stated that the app made her more aware of when she needed a moment to shut down and when she was over- or underchallenged in her current work situation.

Most of the professional care givers reported that the use of the app did not lead to any changes in self-reflection, satisfaction in care, emotional state, care relationship with the PwD or the possibility of maintaining care over a longer period of time. Due to many years of working experience, training and further education, the caregivers have already gained the necessary skills and knowledge, which they considered similar to what is provided via the app. They indicated that they have already successfully built up routines and set up a stress limit that is acceptable to them.

However, three of four formal caregivers agreed, that the SUCCESS app could be especially helpful for informal caregivers, who do not work as professional caregivers.

#### 2.2.3.2 POSSIBLE CHANGES IN CARE FOR FORMAL CAREGIVERS IN HOME CARE

According to the expert from the field of 24-hour home care, the SUCCESS app can have quite positive effects on the working life of formal caregivers who have no specialist training as (health) caregivers. A positive influence on the relationship between caregiver, relatives, and the PwD is conceivable, for example, through suggestions for a meaningful design of everyday life that can be created together.

It was indicated that learning appropriate communication strategies can also have a positive effect on the care relationship, for example, in dealing with aggression and by improving the PwD's response to the caregiver's actions. If the app supports the handling of changes regarding the level of dementia, so that a caregiver can still maintain the care activity, this can positively influence the relationship and trust between all persons involved. Self-reflection was considered critically, because although it is necessary for caregivers of 24-hour care, it cannot be guaranteed that they always have the time and motivation to do so.

#### 2.2.3.3 CHANGES IN CARE FOR INFORMAL CAREGIVERS

Relatives and friends of people with dementia, who tested the SUCCESS app continuously reported about changes that they observed during or after the period of use. The topics describing these changes in care are presented below.

**Aggression:** An important issue is how to deal with aggression and aggressive behavior on behalf of the PwD. Generally, informal caregivers reported that the app enabled them to find appropriate action alternatives in critical situations and that the app supported them in dealing with aggressive feelings and emotions. One test user stated, that the learn & train function of the app helped him/her to deal with his/her own aggression as well as with the partner’s aggression. In the context of preventing verbal aggression, two participants found the self-reflection function very helpful.

**Interaction with the PwD:** Improvements reported by the participants can be seen in the relationship to the PwD, which is based on an interplay of improved communication and interaction with the PwD, a more balanced emotional state of the caregiver through self-reflection and self-care and an increased trust and positive reaction of the PwD, as a result of the more intensive occupation with the subject.

All informal caregivers reported that they became more sensitive to the needs and signals of the PwD. They also realized to be more sympathetic and calm. One test user stated that the app is also very helpful for reminding oneself not to patronize the PwD too much, but to accept wishes and self-determination more understandingly and patiently. Moreover, this test person pointed out that the support in terms of communication and the information about validation could help to avoid that a situation escalates into a dispute or provoked anger (for example when refusing to drink or take medication or repeatedly asking questions after a change of location). The app was considered to be helpful in resolving disputes calmly, communicating one's own needs and limits more sensitively, and helping to cope with changes in the level of dementia.

**Caregiver's life:** All informal caregivers agreed, that the SUCCESS app had a big impact on their daily life regarding various aspects. One participant stated that s/he pays much more attention to the words and phrases that are used during the communication with the PwD. Another test user said it was now easier for him/her to understand specific situations. By using SUCCESS s/he has reached a different level of knowledge and reflection: *"I know that everything is not always as I want it to be. But it is also necessary not to exaggerate and to take some time off. It will then be possible to work under pressure again." (TP8)* Two test users said that the app can serve as a good reminder to take time for oneself.

It was furthermore reported by two participants, that SUCCESS could provide help and problem-solving strategies in critical situations: *"It helps me to find my way when I don't know what to do - when I actually know it theoretically, but don't know what to do at that specific moment and then I will check." (TP6)*

**Self-Care:** The use of the app also reminded the participants to take care of themselves, to set personal limits and to take time for themselves, e.g., by using self-reflection and meditation techniques. Accepting the care activity as a learning process, as well as reflecting and confirming of already existing or learned abilities to act, also increased confidence in care and in the PwD's own competence.

All informal caregivers perceived the self-reflection function as very positive and were very satisfied with the contents provided by the app. Two test users even named the guided meditation as their favourite function or as the most positive experience when interacting with the app.

Only one participant stated that it is now everyone's own responsibility to implement this useful content. S/he himself/herself did read the content of self-reflection in the app but did not make use of it, because s/he had already strategies how to deal with difficult situations, which is illustrated in the following statement: *"If I have problems, I go to the forest". (TP6)*

**Resources:** Most of the users reported that they were encouraged by the app to ensure their own resilience and to reflect on their crisis management strategies as well as on available or required resources. They were encouraged to think about if there are other people who could relieve them, although this does not mean that someone is already there to help. The use of SUCCESS made participants aware of the need to pay attention to whether further resources need to be activated.

Romania

### 2.2.3.4 CHANGES FOR FORMAL CAREGIVERS

For Romania, there was only one formal caregiver included in the qualitative trial. As s/he had over ten years of experience of providing care for PwD, s/he did not report any changes following the use of the app in any of the following dimensions: self-reflection, satisfaction in care, emotional state, care relationship with the PwD or the possibility of maintaining care over a longer period of time. However, she evaluated the app as potentially being very useful for informal carers, who find it difficult to adjust their behaviour in the beginning stages when they are slowly learning more about Dementia *("It will be useful for family members because their job becomes easier once they understand how to manage the behavioural and psychological problems of PwD."(TP9)).*

### 2.2.3.5 CHANGES FOR INFORMAL CAREGIVERS

**Aggression:** A better understanding of the aggressive behaviours of PwD was one of the main benefits highlighted by informal caregivers. One participant mentioned that the most positive experience with SUCCESS was to learn more about aggression after her mother had a violent reaction. The information provided via the app helped her to understand that his/her mother's behaviour might be due to the disease and helped him/her to better react.

**Interaction with the PwD:** In terms of interaction with PwDs, the main impact of using the SUCCESS app was at the level of better understanding the behavioural and psychological problems of PwD. Two categories of changes in understanding were prevalent: a) following the diagnosis, some carers limited the tasks and involvement of PwD in most types of actives in order to protect them *"I thought she would feel better if I don't involve her in daily activities"(TP13)*. For them, the app provided a good basis for understanding that keeping PwD active is very important for slowing down the cognitive and functional decline of the PwD, while maintaining a good quality of life for the PwD; b) the second category of users continued to treat the PwD as a normal person after the diagnosis, which also meant that they would easily get upset and/or criticize the PwD for any "mistake" they would make. For them, the use of the SUCCESS app provided more information about the behavioural and psychological problems experienced by PwD and the appropriate behaviours to have in response to these *("My mother is functional but by using the app I have realised that my mother has a serious problem and that I need to learn how to interact. I had the tendency to treat her as a normal person and I was criticizing her when she was doing something wrong. Now I don't do that anymore. I don't have to get mad when she does something wrong. I have to stay calm. The information about activities that can be planned for the PwD was also very helpful." - TP13*).

Another user mentioned that the suggestions for activities helped her better plan for joint activities with her mother *("During the trial period we better worked together and she was more willing to cooperate, I reserved more time for planning activities together; My mother is not the person I knew; she is a different person. The app helped me see her with different eyes and to avoid taking everything she says personally. I tried to use the suggestions for interaction included in the app for anger and mistrust and it worked"TP10).*

Another user was initially enthusiastic about the SUCCESS app, when contacted after the first week of the trial. S/he reported having successfully tried out several of the strategies included in the app. However, at the final interview s/he was rather pessimistic about the changes in the interaction with her husband *("What I have now understood is that there is not much I can do. He refuses to go out and is lethargic most of the day" TP14).*

**Caregiver's life and self-care:**

Two of the nine participants reported that they used the guided meditation frequently as a way to relax at the end of the day. Both of them reported having tried beforehand several relaxation techniques but preferred to use the video included in the app because it was in Romanian and easy to find in the app.

One participant was particularly enthusiastic about the diary function which s/he reported being the favourite feature of the app. S/he indicated that she frequently used it during the trial.

Secondary benefits of using the app were also reported by one participant, who mentioned that, due to the app, s/he could provide advice to a friend, who was recently accused of stealing something from an elderly person *("I could help a friend which was accused that she stole something; I showed her the app, she understood that it might be a symptom and she didn't take it personally anymore" TP10*).

Due to many years of working experience, training and further education, the formal caregivers had already gained the necessary skills and knowledge, so the app didn't lead to major changes in self-reflection, satisfaction in care, emotional state or care relationship with the PwD.

In contrast, all informal caregivers agreed that the app in fact did lead to positive changes in the interaction with the PwD, in their own lives and in their self-reflection. In addition, the content of the app influenced important everyday challenges such as aggression and the correct use of resources in a positive way.

## 2.3 IMPLICATIONS

The following list includes a summary of all issues regarding the functionalities and the content of the SUCCESS app, that were found during the first SUCCESS field trial in Austria and Romania.

Issues found in both countries are **colored black**, issues only found in Austria are **colored blue**, issues only found in Romania are **colored green**.

Table 7: Most urgent Issues (Prio 1)

| Category | Description | Suggestions for improvement |
|---|---|---|
| App crashes | App crashes quite often, especially<br>• when using the “back” arrow<br>• when trying to leave the avatar role-play<br>• during avatar-lectures<br>• during “Selbstreflexion” (self-reflection) function (e.g. after tapping “5-Minuten-Meditation”<br>• when quickly moving through the app | • reasons for bugs needs to be checked |
| Role-play | • Users could not easily navigate through the role-play / could not easily make use of the role play<br>• Reasons include:<br>• Avatar did not speak in some cases (hence, users were not sure what to do next)<br>• Unclear what user is supposed to do (e.g. how to start the conversation)<br>• Unclear (partially no) function (or functioning) of the arrow or answer buttons at the bottom<br>• “back” arrow did not work<br>• Loads very slowly /does not work properly when used too fast | • Make sure Avatar always speaks during his part of the conversation (bug?)<br>• Only show buttons if they have a function; change the appearance of the button if it changes its function or add a transition animation, e.g., hide and show buttons, when new commands appear<br>• Make sure navigational buttons work properly |
| Avatar | Appearance of the avatars was strongly criticized.<br>Especially the female lecture-avatar “looks and sounds unnatural” (e.g. claw-like hand, hair, teeth and outfit). Expressions and movements do not look appealing and realistic but rather threatening. Role-play avatar (especially female) looks neglected, mean/angry/unnatural<br>The old female avatar also looks scary<br>The avatar cannot be personalized (hair, clothes, etc.)<br>The movements of the avatar are rigid<br>Not clear why the avatar places the hands on the hips | • Needs to be discussed with Emanuel<br>• Improve appearance (especially of female avatars)<br>• Give more avatar options or the possibility to personalize the avatar<br>• Make movements more natural and flexible |

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| | | • Show only the upper part of the avatar |
| “Selbstreflexion” (self-reflection) | Users could not easily navigate through self-reflection.<br>Reasons include:<br>• Too much happening on the intro screen<br>• unclear what users are supposed to do, (e.g. “next” button has no function)<br>• Users did not understand that the “intro” button in the end led back to the beginning because the module was completed | • Allow user to pause, mute and continue avatar monolog<br>• make sure avatar speaks within all parts of the module<br>• Rename navigational buttons so that their function is clear → suggestions could be directly added to translation list (AIT)<br>• *To be discussed with AIT designer Michael* |
| Quick-help | Not all participants realized that the Quick-Info is a function in itself.<br>It was not clear how to use the function<br>App crashes when searching for keywords with no results | • There seems to be still a problem to understand the overall function “quick help” – we need to look into this in detail …<br>• *To be discussed with AIT designer Michael*<br>• Add explanatory text above /in search bar; e.g. “What kind of tip are you searching for?” or grey out suggestion in search bar<br>• more key-words/synonyms so that results are displayed – avoid that the app crashes due to the lack of key words<br>• Provide a solution if there are no key-words for a search (e.g. show keywords for which tips are available) |

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| Avatar Lecture „ein sinnvolles Leben schaffen“ | Avatar only speaks during the intro and when choosing “Work”, but not during the other options. Then again the avatar starts speaking every time the user returns to the intro | *(See also suggestions/comments for “self-reflection” above)*<br>• incorporate Avatar throughout the entire lecture<br>• option to pause, mute and continue the avatar lecture<br>• Rename navigational buttons so that their function is clear |

Table 8: Issues Prio 2-4

| Category | Description | Suggestions for improvement |
|---|---|---|
| OTHER ISSUES (Prio 2) | | |
| Language | Many parts are in English even when using the German/Romanian version e.g.:<br>- Diary prompt<br>- Content category names<br>- Tools menu<br>- Description text role-play "verbal aggression"<br>- Buttons in "Selbstreflexion" (self reflection function) | - Translate parts that are in the wrong language |
| Performance of app | App is very slow, especially in the sections with the avatar<br>Users reported the temptation to press repeatedly on the arrows or on the avatar; they also tried to drag the text on the avatar to get a reaction from the avatar | - Improve performance of app/avatar content elements<br>- Drag text on top of the avatar? (TBD) |
| Text/Avatar text | There are many grammar and language mistakes and even nonsense (Selbstreflexion -> Regenerierung sometimes it just mentions Doktor Kristin Neff out of nowhere. Roleplay „Aggression/persönliche Wut" is missing a word in line 8…) throughout the app. Have a look at the avatar monolog text, as it appears while the avatar is speaking capital letters and punctuation are neglected but when tapping on the avatar the full text appears in an improved version. | - Improve text, especially grammar and sentence structure |
| Voice of the avatar (Romanian version of App) | The voice of the young male avatar is the voice of a woman in the diary;<br>In the lecture part of the app the male avatar does not speak at all<br>The young woman does not speak at all neither in the diary section nor in the lecture<br>The voice is unpleasant (metallic/digital) | - Change the voice of the young avatar with a male voice in the diary section<br>- Check the text to speech<br>- Improve the voice of the avatar |
| Text to speech (Romanian version of App) | For text to speech, sometimes the pronunciation is completely wrong. It might be due to diacritics or punctuation | - Check whether the pronunciation can be improved by correcting punctuation and/or diacritics |
| Readability | Participants found articles difficult to read.<br>- Grammar and spelling mistakes, incomplete and wrong sentence interfere with pleasant reading experience | - Add paragraphs, highlights, improve grammar etc. to make text structure more appealing |

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| Personalization | The tool function at the top right includes a huge amount of options but users have trouble finding (all of) them | • Allow users to create their profile when tapping on the circle in the middle (e.g. add name and use this name in the diary prompt and Avatar conversations), allow for avatar personalization here. Make progress visible in profile, allow filtering for content, etc.<br>• Move diary to "Selbstreflexion", make diary entries visible<br>• So that the tool function only includes technical-settings |
| Change Avatar | Users have difficulties changing the avatar from female to male. | • Make avatar change option more salient, e.g. in profile option (when tapping on the circle in the center)<br>• Make Avatar personalization possible (e.g. By allowing to change name and using this name in role-play) |
| Summary under videos | Most videos (except for „Geführte Meditation“) do not have an introduction, description or summary | • Add summary text like for video „Geführte Meditation” |
| Home screen | Sometimes it is difficult to return to the home screen | • Provide a uniform way to return to the home screen from all parts of the app |
| Amount of content (Learn and train) | Users missed information on certain topics/situations:<br>• Roleplay on the topic „I want to leave!“/ Running away<br>• Aggression against PwD (domestic violence)<br>• Content related to situations that affect the freedom and autonomy of individuals with less advanced dementia, e.g.<br>• The person is still driving, to what extent is it safe and what to do if the person gets lost?<br>• The person does not want to be placed in a care home, how can the transition be arranged?<br>• content for dealing with younger people who become demented | • Additional content to be provided |

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| | • first steps after diagnostic | |
| Amount of content (Activities) | At the moment, there is almost no content available in the category “Activities”; users proposed:<br>• Memory training<br>• Creative activities with music, coloring etc.<br>• Train patience with PwD<br>• Quizzes | • Additional content to be provided |
| Content (Quick-help) | Due to missing keywords (synonyms), certain content elements are hard to find | • Provide additional keywords for content elements |
| Content (Formal caregivers) | Formal caregivers with proper training would need much more detailed information in order to gain extra advantages from using the app | • TBD |
| OTHER ISSUES (Prio 3) | | |
| Diary prompt | • User reports that sometimes diary prompt leads to the diary even when “cancel” is selected<br>• Users were bothered by the prompt<br>• Users thought that the self-reflection was important but did not do it because they didn’t have the time | • If this is a bug it may be fixed<br>• rename the buttons to make clear which button will lead to the diary and which one wont (e.g. “I’ll do it later” and “Write diary”)<br>• Allow to set reminder for diary/self-reflection to a self-chosen time |
| Content box | The last box for each content (e.g. the last box with a preview of the article) is not completely visible | • Adjust spacing so that the entire content-box is visible |
| Filter content | Not all content in the learn &train function is relevant for informal vs. formal caregivers or caregivers of people with different levels of dementia<br>Info for the post-diagnostic period (e.g. general info, local resources, etc.)<br>The suggestions for reactions/activities are also not particularized for different stages of dementia | • Add option to filter content<br>• Add option to sort for favorites<br>• Add new articles<br>• Recommend activities/reactions based on the level of dementia |
| Links in Articles | • Links are read out loud with all special characters<br>• Links are not clickable | • Turn links into hyperlinks |

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| Role-play | Introductory text too long | • Make text structure of introduction more appealing by dividing text into paragraphs (e.g. one paragraph description of the situation at hand, second paragraph theoretical background info) and adding highlights, while leaving out irrelevant sentences |
| Avatar lectures | Structuring of visual text output | • add paragraphs, highlights etc. |
| OTHER ISSUES (Prio 4) | | |
| Title for content | Article with the title “Bewegungsstörungen” is actually an article on “Verstecken und verlieren ” | • Change Article |
| | Video with title „Medikamentenverweigerung“ is actually the same video as „Kommunikation mit Menschen mit schwerer Demenz“ | • Change Video |
| Enlarge video | User did not find option to make video larger or the video stopped when screen was tilted | • TBD |
| Video subtitles | Video subtitles are incorrect/nonsense | • Change subtitles |
| Link from quick-help to learn & train | Quick help contains simple tips but no in-depth information. | • Add a link from the quick-tip to the relevant Article, Video, Lecture or Roleplay in the Learn & Train Function |
| Content images | The image next to the content is not descriptive (e.g. image of the “Lernen & trainieren” function is the image from the “Aktivitäten” function; every image is the same)<br>Images to choose an avatar do not show the right avatars | • Use different and more representative images for different content |
| Use of multiple languages | Missing subtitles/translations for videos / Bugs related to multi-language support | • Provide translations/subtitles to the videos<br>• Fix bug within progress counter, progress ring (counter goes above 100% when reading articles in multiple languages) |
| Self reflection | Nice-to-have features for self-reflection part | • Give opportunity to see past entries (e.g. action list)<br>• Integrate diary in this |

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| | | function (TBD) |
| Calendar | No possibility to plan for an action | • Link the app to a calendar where actions could be planned OR have a planning section |

# 3 SECOND FIELD TRIAL

## 3.1 SAMPLE DESCRIPTION

Overall the baseline sample of the second field trial consisted of 69 participants. Table 9 provides an overview on the number of responses for measurement points T0 (baseline), T1 (1 month), T2 (3 months) and T3 (6 months).

Table 9: Participants per country (*N*= 69)

| Country | T0 | T1 | T2 | T3 |
|---|---|---|---|---|
| Austria | 37 (53.6%) | 27 (39.1%) | 17 (24.6%) | 20 (29.0%) |
| Romania | 31 (44.9%) | 15 (21.7%) | 21 (30.4%) | 14 (20.3%) |
| Missing | 1 (1.4%) | 27 (39.1%) | 31 (44.9%) | 35 (50.7%) |

55 (80.9 %) of participants in the pooled sample were female, 13 (19.1 %) male. Table 10 provides an overview on the gender distribution.

Table 10: Gender distribution (*N* = 68)

| | | | Country | | |
|---|---|---|---|---|---|
| | | | Romania | Austria | Total |
| Gender | Male | Count | 10 | 3 | 13 |
| | | % within Gender | 76.9% | 23.1% | 100.0% |
| | | % within Country | 27.0% | 9.7% | 19.1% |
| | | % of Total | 14.7% | 4.4% | 19.1% |
| | Female | Count | 27 | 28 | 55 |
| | | % within Gender | 49.1% | 50.9% | 100.0% |
| | | % within Country | 73.0% | 90.3% | 80.9% |
| | | % of Total | 39.7% | 41.2% | 80.9% |
| Total | | Count | 37 | 31 | 68 |
| | | % within Gender | 54.4% | 45.6% | 100.0% |
| | | % within Country | 100.0% | 100.0% | 100.0% |
| | | % of Total | 54.4% | 45.6% | 100.0% |

Overall, the mean age of the participants of the 2nd field trial is 47.29 years (*SD* = 14.11). (see Table 11).

Table 11: Mean age of participants (*N* = 68)

| Country | *M* | *n* | *SD* |
|---|---|---|---|
| Romania | 44.54 | 37 | 14.88 |
| Austria | 50.58 | 31 | 12.58 |
| Total | 47.29 | 68 | 14.11 |

In the pooled sample, 38 (55.9%) were informal caregivers and 30 (44.1%) formal caregivers (see Table 12).

Table 12: Distribution of informal and formal caregivers (*N* = 68)

| Caregiver type | Romania | Austria | Overall |
|---|---|---|---|
| Informal caregivers | 30 (81.0%) | 8 (25.8%) | 38 (55.9%) |
| Formal caregivers | 7 (19.0%) | 23 (74.2%) | 30 (44.1%) |
| Total | 37 (100%) | 31 (100%) | 68 (100.0%) |

### Sample Austria

The Austrian baseline sample consisted of 31 participants, of which 28 (90.3 %) were female and 3 (9.7 %) male. 8 (25.8 %) were informal caregivers and 23 (74.2 %) formal caregivers.

Austrian formal caregivers were mainly recruited by contacting health care organizations in Lower Austria and Vienna (in total over 80 organizations contacted). In addition to the involvement of formal caregivers, these organisations also informed their clients (e.g. in day care centres) about the possibility to participate as informal caregiver. Informal caregivers were mainly recruited via the network of EURAG Austria, by contacting self-help groups (e.g. in Krems) and by participating in relevant senior events.

Table 13: Demographic Data Participants Austria

| ID (formal/ informal) | Gender | Age | Highest completed education | Occupation |
|---|---|---|---|---|
| AT1 (formal) | female | 67 | university degree | retired/ voluntary service |
| AT2 (informal) | female | 57 | secondary school | full-time employed |
| AT3 (informal) | female | 63 | technical/ vocational high school | retired |
| AT4 (informal) | male | 69 | general qualification for university entrance (high school) | retired |
| AT5 (formal)* | female | 63 | professional school/ apprenticeship | retired/ voluntary service |
| AT6 (formal) | female | 80 | professional school/ apprenticeship | retired |

| | | | | |
|---|---|---|---|---|
| AT7 (informal) | female | 34 | university degree | part-time employed |
| AT9 (informal) | female | 55 | university degree | part-time employed |
| AT10 (formal) | female | 58 | secondary school | full-time employed |
| AT11 (formal) | female | 32 | professional school/ apprenticeship | full-time employed |
| AT12 (formal) | female | 50 | n.a. | part-time employed |
| AT13 (formal) | female | 38 | professional school/ apprenticeship | part-time employed |
| AT14 (formal) | female | 27 | general qualification for university entrance (high school) | full-time employed |
| AT15 (formal) | female | 55 | general qualification for university entrance (high school) | part-time employed |
| AT16 (formal) | female | 40 | professional school/ apprenticeship | part-time employed |
| AT18 (formal) | female | 54 | professional school/ apprenticeship | part-time employed |
| AT20 (formal) | female | 62 | professional school/ apprenticeship | part-time employed |
| AT21 (formal) | female | 31 | secondary school | part-time employed |
| AT22 (formal) | female | 39 | professional school/ apprenticeship | part-time employed |
| AT24 (formal) | female | 40 | compulsory school | part-time employed |
| AT25 (formal) | female | 55 | compulsory school | part-time employed |
| AT27 (formal) | female | 47 | compulsory school | part-time employed |
| AT28 (formal) | female | 39 | technical/ vocational high school | part-time employed |
| AT29 (formal) | female | 51 | university degree | part-time employed |
| AT30 (formal) | female | 47 | professional school/ apprenticeship | part-time employed |
| AT32 (formal) | female | 55 | professional school/ apprenticeship | full-time employed |
| AT33 (formal) | female | 46 | n.a. | part-time employed |
| AT34 (formal) | female | 41 | professional school/ apprenticeship | part-time employed |
| AT35 (informal) | female | 60 | professional school/ apprenticeship | retired |
| AT36 (informal) | male | 64 | secondary school | retired |
| AT37 (formal) | female | 48 | university degree | part-time employed |
| AT38 (informal) | male | 64 | professional school/ apprenticeship | retired |

* TP5 did not complete the T0 questionnaire, thus she is excluded from the analysis of the demographic data

### Sample Romania

The final Romanian sample consisted of 37 participants, of which 27 (73.0%) were female and 10 (27.0%) male. 30 (81.0%) were informal caregivers and 7 (19.0%) formal caregivers.

In Romania both formal and informal caregivers have been recruited via the Memory Center ran by the Romanian Alzheimer Society and located on the premises of the psychiatric hospital Alexandru Obregia.

Informal caregivers of patients with dementia who used the services of the Memory Center in a time frame of about 6 months have been informed about the SUCCESS study and – If they met the inclusion criteria - have been invited to consider registering for the study.

Table 14: Demographic Data Participants Romania

| ID (formal/ informal) | Gender | Age | Highest completed education | Occupation |
|---|---|---|---|---|
| RO1 (informal) | male | 47 | high school | part-time employed |
| RO2 (informal) | female | 29 | university degree | full-time employed |
| RO3 (formal) | female | 30 | university degree | full-time employed |
| RO4 (informal) | female | 40 | university degree | full-time employed |
| RO5 (informal) | male | 67 | university degree | retired |
| RO6 (informal) | male | 39 | university degree | full-time employed |
| RO7 (informal) | male | 54 | university degree | full-time employed |
| RO8 (informal) | female | 40 | university degree | full-time employed |
| RO9 (informal) | female | 60 | university degree | retired |
| RO10 (informal) | female | 31 | university degree | full-time employed |
| RO11 (informal) | female | 34 | university degree | full-time employed |
| RO12 (informal) | female | 58 | university degree | full-time employed |
| RO13 (informal) | female | 58 | university degree | full-time employed |
| RO14 (informal) | male | 62 | university degree | full-time employed |
| RO15 (informal) | female | 59 | professional school/ apprenticeship | retired |
| RO16 (informal) | female | 52 | technical/ vocational high school | full-time employed |
| RO17 (informal) | female | 42 | university degree | full-time employed |
| RO18 (informal) | female | 48 | university degree | full-time employed |
| RO19 (informal) | female | 29 | university degree | on maternity leave |
| RO20 (informal) | female | 58 | university degree | full-time employed |

| | | | | |
|---|---|---|---|---|
| RO21 (informal) | female | 42 | university degree | student/person in educational training |
| RO22 (informal) | female | 47 | high school | full-time employed |
| RO23 (informal) | female | 68 | technical/ vocational high school | retired |
| RO24 (formal) | male | 74 | technical/ vocational high school | retired |
| RO25 (informal) | female | 27 | university degree | full-time employed |
| RO26 (informal) | male | 62 | university degree | part-time employed |
| RO27 (formal) | female | 25 | university degree | full-time employed |
| RO28 (informal) | female | 54 | university degree | full-time employed |
| RO29 (formal) | female | 25 | university degree | full-time employed |
| RO30 (formal) | female | 26 | university degree | full-time employed |
| RO31 (formal) | male | 28 | university degree | full-time employed |
| RO32 (informal) | female | 28 | university degree | full-time employed |
| RO33 (informal) | male | 19 | high school | student/person in educational training |
| RO34 (formal) | male | 57 | university degree | full-time employed |
| RO35 (informal) | female | 51 | high school | full-time employed |
| RO36 (informal) | female | 50 | high school | full-time employed |
| RO37 (informal) | female | 28 | university degree | full-time employed |

## 3.2 QUANTITATIVE RESULTS

In the following chapters, the main results of the second field trial are described: chapter 3.2 summarizes quantitative outcomes, chapter 3.3 the results of a first analysis of the qualitative data. This chapter is structured according to our central objectives.

### 3.2.1 BURDEN OF CARE

The impact on burden of care was assessed by applying the *Zarit caregiver burden scale* (see D5.1) at T0, T2 and T3, i.e. at baseline, after 3 months and after 6 months.

**Informal caregivers**

Figure 1 provides an overview on the evolution of mean scores for burden of care between time points T0 (baseline), T2 (after month 3) and T3 (after month 6) for informal caregivers.

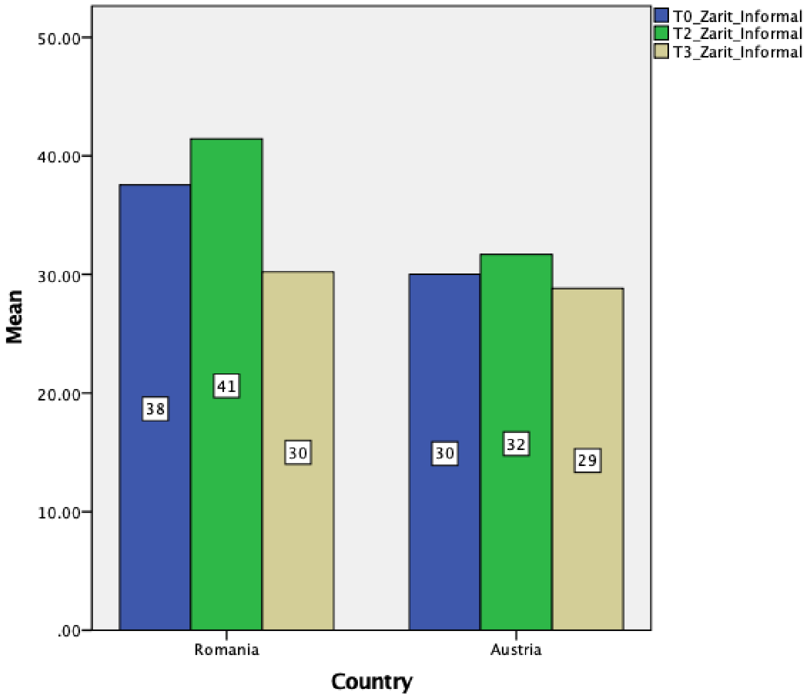

Figure 1: Evolution of mean scores (range 0-84) for burden of care between time points T0, T2 and T3 (Informal caregivers)

Comparing the mean scores from baseline to T2 and T3, a common pattern can be observed both for Romania and Austria: in T2 the scores increase as compared to the baseline but in T3 they drop below the scores obtained at the baseline assessment. These differences are not statistically significant. However, taking into consideration the low number of participants and the big absolute value differences, we would expect this observed tendency to become statistically significant in a larger trial.

One explanation can be that by being exposed to detailed information about the behavioural and psychological problems that people with dementia might have, caregivers are more inclined to overestimate the burden they experience in T2. However, once the accommodation with the app and the information provided by it takes place, the scores drop below baseline levels which might be an effect of the fact that caregivers might have had a chance to try some of the practical advice provided by the SUCCESS app which, in turn, has helped them with the perceived burden of care.

Table 15: Evolution of degree of burden between time points T0, T2 and T3 (Informal caregivers)

| Degree of burden | T0 (baseline) | T2 (3 months) | T3 (6 months) |
|---|---|---|---|
| Little or no burden | 5 (13.2%) | 3 (12.5%) | 6 (28.6%) |
| Mild to moderate burden | 18 (47.4%) | 9 (37.5%) | 7 (33.3%) |
| Moderate to severe burden | 13 (34.2%) | 9 (37.5%) | 7 (33.3%) |
| Severe burden | 2 (2.3%) | 3 (12.5%) | 1 (4.8%) |
| **Total** | **38 (100%)** | **24 (100%)** | **21 (100%)** |

Table 15 provides an overview on the evolution of the degree of burden of informal caregivers between time points T0 (baseline), T2 (after month 3) and T3 (after month 6). Quartiles were used to define the four categories for degree of burden: “Little or no burden”, “Mild to moderate burden”, “Moderate to severe burden” and “Severe burden”.

The majority of informal caregivers (66.6% - 81.6%) have experienced mild to moderate or moderate to severe burden of care throughout the trial period. The number of people experiencing little or no burden at the six-month follow up has more than doubled (28.6% compared to initial 13.2%).

**Formal caregivers**

Figure 2 provides an overview on the evolution of mean scores for burden of care between time points T0 (baseline), T2 (after month 3) and T3 (after month 6) for formal caregivers.

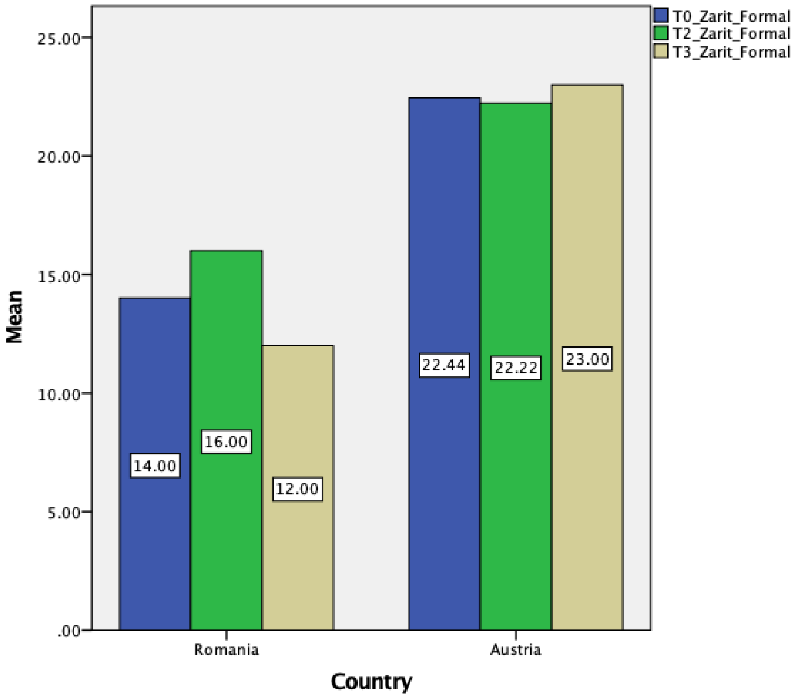

Figure 2: Evolution of mean scores (range 0-56) for burden of care between time points T0, T2 and T3 (Formal caregivers)

For Romanian formal caregivers, the evolution of average scores during the 6-month trial period follows a similar pattern as described for informal caregivers. For Austria, scores have remained constant, with negligible variations observed.

The observed differences might have two causes: firstly, the profile of the caregivers in the two countries is different (in Austria one part of the involved formal caregivers work in a care home and have more contact with the PwD, while in Romania involved caregivers provide care during a limited timeframe) and, secondly there might be an imbalance in the levels of previous knowledge on the topic that caregivers in Austria might have as compared with caregivers in Romania.

Table 16: Evolution of degree of burden between time points T0, T2 and T3 (Formal caregivers)

| **Degree of burden** | **T0 (baseline)** | **T2 (3 months)** | **T3 (6 months)** |
|---|---|---|---|
| Little or no burden | 8 (28.6%) | 1 (7.1%) | 2 (15.4%) |
| Mild to moderate burden | 12 (42.9%) | 12 (85.7%) | 11 (84.6%) |
| Moderate to severe burden | 8 (28.6%) | 1 (7.1%) | - |
| Severe burden | - | - | - |
| **Total** | **28 (100%)** | **14 (100%)** | **13 (100%)** |

Table 16 provides an overview on the evolution of the degree of burden of formal caregivers between time points T0 (baseline), T2 (after month 3) and T3 (after month 6). Quartiles were used to define the four categories for degree of burden: “Little or no burden”, “Mild to moderate burden”, “Moderate to severe burden” and “Severe burden”.

The majority of the formal caregivers experience mild to moderate burden (42.9% - 85.7%), some experience little or no burden and none of the formal caregivers report severe burden throughout the trial period.

**Informal vs. formal caregivers**

Table 17: Comparison of informal and formal caregivers’ mean burden category

| | T0_Zarit_Informal_average | T0_Zarit_Formal_average | T2_Zarit_Informal_average | T2_Zarit_Formal_average | T3_Zarit_Informal_average | T3_Zarit_Formal_average |
|---|---|---|---|---|---|---|
| *M* | 1.6603 | 1.5024 | 1.8049 | 1.4619 | 1.4567 | 1.4154 |
| *N* | 38 | 28 | 24 | 14 | 21 | 13 |
| *SD* | .66214 | .68071 | .75473 | .41218 | .80654 | .38601 |
| Minimum | .36 | .33 | .23 | .80 | .23 | .80 |
| Maximum | 3.18 | 2.87 | 2.86 | 2.07 | 2.82 | 1.93 |

When comparing formal and informal caregivers, in terms of impact on the perceived burden category they found themselves in, the SUCCESS app seems to have a higher impact on the informal caregivers rather than on the formal caregivers.

### 3.2.2 CAREGIVER SATISFACTION & RELATIONSHIP

The impact on caregiver satisfaction was assessed by applying the *Carer's Assessment of Satisfaction Index (CASI)* (see D5.1) at T0, T2 and T3, i.e. at baseline, after 3 months and after 6 months.

### Overall assessment

Table 18: Mean scores Carer's Assessment of Satisfaction Index (CASI)

| | *n* | Minimum | Maximum | *M* | *SD* |
|---|---|---|---|---|---|
| T0_CASI_Scale1 | 66 | .00 | 39.00 | 22.4394 | 11.78412 |
| T0_CASI_Scale2 | 66 | .00 | 39.00 | 21.3333 | 11.15393 |
| T0_CASI_Scale3 | 66 | .00 | 12.00 | 6.4091 | 3.71681 |
| T2_CASI_Scale1 | 38 | 2.00 | 39.00 | 23.4211 | 9.89029 |
| T2_CASI_Scale2 | 38 | 2.00 | 39.00 | 21.7632 | 8.89103 |
| T2_CASI_Scale3 | 38 | .00 | 12.00 | 6.1316 | 2.72299 |
| T3_CASI_Scale1 | 34 | .00 | 39.00 | 24.5882 | 10.21917 |
| T3_CASI_Scale2 | 34 | 2.00 | 39.00 | 21.7647 | 10.38081 |
| T3_CASI_Scale3 | 34 | .00 | 12.00 | 6.5294 | 3.37760 |
| Valid N (listwise) | 27 | | | | |

Table 18 provides an overview on the evolution of the mean CASI scores (informal and formal caregivers) between time points T0 (baseline), T2 (after month 3) and T3 (after month 6). When looking at this pooled sample of participants, the satisfaction with care perceived by caregivers has linearly increased during the trial in one of the three scales of the instrument, the one referring to factors related to the person that is cared for.

### Romanian vs. Austrian caregivers

Figure 3 provides an overview on the evolution of mean CASI scores (informal and formal caregivers), comparing Austrian and Romanian participants.

When splitting the results per country an increase in all scales for the Romanian sample and slight decreases in satisfaction for the Austrian sample can be observed. These results might be due to the different sample composition, in the Romanian subgroup the informal caregivers being more numerous than the formal caregivers while in the Austrian sample the formal caregivers are more numerous.

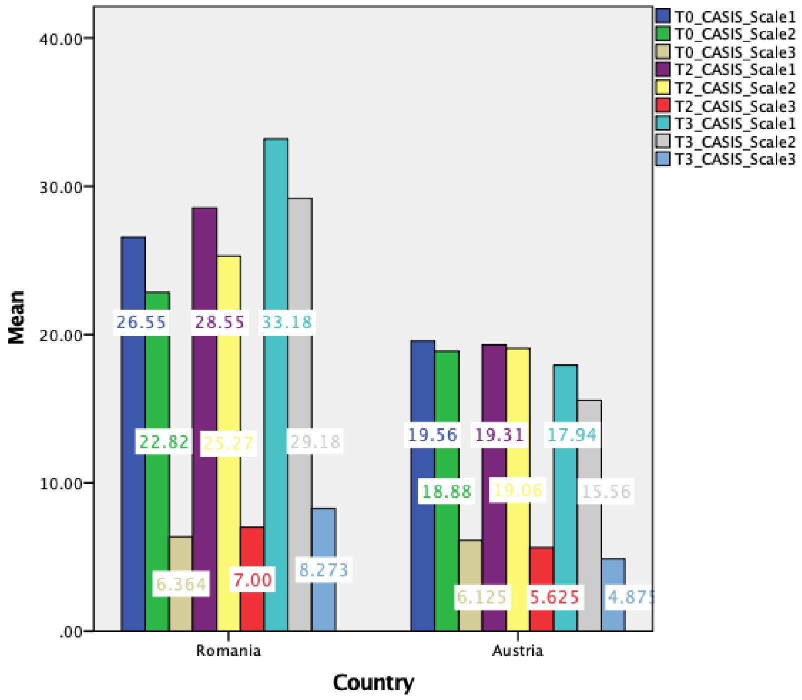

Figure 3: Comparison mean scores Carer's Assessment of Satisfaction Index (CASI) Austrian/Romanian participants (range 0-60)

### Informal vs. formal caregivers

Comparing CASI mean scores for informal and formal caregivers, the mean scores obtained by the informal caregivers are higher for all assessment periods and for all the subscales (not significant) (see Table 19).

Table 19: Carer's Assessment of Satisfaction Index (CASI) average scores by country

| Caregiver type | | T0_CASI _Scale1 | T0_CASI _Scale2 | T0_CASI _Scale3 | T2_CASI S_Scale1 | T2_CASI S_Scale2 | T2_CASI S_Scale3 | T3_CASI S_Scale1 | T3_CASI S_Scale2 | T3_CASI S_Scale3 |
|---|---|---|---|---|---|---|---|---|---|---|
| in-formal | *M* | 24.1053 | 23.4211 | 6.9737 | 24.7619 | 23.0952 | 6.1429 | 27.4444 | 25.7222 | 7.7222 |
| | *n* | 38 | 38 | 38 | 21 | 21 | 21 | 18 | 18 | 18 |
| | *SD* | 11.37753 | 11.71193 | 3.76676 | 10.57310 | 9.36432 | 2.79796 | 8.73278 | 8.95614 | 3.08327 |
| formal | *M* | 20.1786 | 18.5000 | 5.6429 | 21.7647 | 20.1176 | 6.1176 | 20.8667 | 16.8667 | 5.0000 |
| | *n* | 28 | 28 | 28 | 17 | 17 | 17 | 15 | 15 | 15 |
| | *SD* | 12.15350 | 9.85262 | 3.57164 | 9.01061 | 8.24532 | 2.71299 | 11.26224 | 10.50759 | 3.29502 |
| Total | *M* | 22.4394 | 21.3333 | 6.4091 | 23.4211 | 21.7632 | 6.1316 | 24.4545 | 21.6970 | 6.4848 |
| | *n* | 66 | 66 | 66 | 38 | 38 | 38 | 33 | 33 | 33 |
| | *SD* | 11.78412 | 11.15393 | 3.71681 | 9.89029 | 8.89103 | 2.72299 | 10.34738 | 10.53413 | 3.41981 |

### 3.2.3 BEHAVIORAL PROBLEMS OF PWD

The impact on behavioural problems of the PwD was assessed by applying the *Neuropsychiatric Inventory Questionnaire (NPI-Q)* (see D5.1) at T0 and T3, i.e. at baseline and after 6 months. It includes 12 domains: Delusions, Hallucinations, Agitation/Aggression, Dysphoria/Depression, Anxiety, Euphoria/Elation, Apathy/Indifference, Disinhibition, Irritability/Lability, Aberrant Motor, Night time Behavior, Appetite/Eating. For each of these domains, caregivers were asked: (1) whether the symptom is present (responses to each domain question are "Yes" (present) or "No" (absent)); (2) if "Yes", the caregiver then rates both, the Severity of the symptoms present within the last month on a 3-point scale, and the associated impact of the symptom manifestations on them (i.e. Distress) using a 5-point scale.

The NPI-Q provides symptom Severity and Distress ratings for each symptom reported, and total Severity and Distress scores reflecting the sum of individual domain scores.

**Overall assessment**

Our results show that absolute average scores have decreased both for severity of symptoms as well as for distress experienced by the caregivers. However, due to drop out of participants resulting in a total sample of 33 participants for this analysis, these differences are statistically significant only for distress. The big differences in absolute mean values and the low number of participants are suggesting that the results for distress would become significant in a larger sample.

Table 20: Descriptive statistics Neuropsychiatric Inventory Questionnaire (NPI-Q)

| | *n* | Minimum | Maximum | *M* | *SD* |
|---|---|---|---|---|---|
| Severity T0 | 68 | .00 | 32.00 | 12.94 | 6.84 |
| Severity T3 | 33 | 2.00 | 24.00 | 9.57 | 5.66 |
| Distress T0 | 68 | .00 | 43.00 | 14.23 | 9.51 |
| Distress T3 | 33 | .00 | 34.00 | 11.06 | 8.34 |
| Severity x Distress T0 | 67 | .00 | 126.00 | 32.52 | 25.20 |
| Severity x Distress T3 | 35 | .00 | 102.00 | 22.51 | 21.82 |
| Valid N (listwise) | 33 | | | | |

| Paired Samples Test | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| Differences between baseline (T0) and 6 month follow-up (T3) | Paired Differences | | | | | *t* | *df* | Sig. (2-tailed) |
| | *M* | *SD* | *SEM* | 95% CI | | | | |
| | | | | Lower | Upper | | | |
| SEVERITY | 3.00000 | 7.06222 | 1.22938 | .49584 | 5.50416 | 2.440 | 32 | .020 |
| DISTRESS | 2.30303 | 10.90437 | 1.89821 | -1.56349 | 6.16955 | 1.213 | 32 | .234 |
| SEVERITY X DISTRESS | 8.57143 | 30.36957 | 5.13339 | -1.86088 | 19.00374 | 1.670 | 34 | .104 |

### Romanian vs. Austrian caregivers

Table 21 provides a comparison of Romanian and Austrian NPI scores. When looking at the differences between countries, a difference in the level of distress as well as in the total scores (severity x distress) are observed at T0, with the higher scores being observed in Romania. However, at the end of the trial these differences are not observable anymore.

Table 21: NPIQ average scores by country

| Country | | T0 Severity | T0 Distress | T3 Severity | T3 Distress | T0 Severity x Distress | T3 Severity x Distress |
|---|---|---|---|---|---|---|---|
| Romania | *M* | 13.16 | 17.56 | 8.64 | 11.42 | 39.02 | 19.56 |
| | *n* | 37 | 37 | 14 | 14 | 36 | 16 |
| | *SD* | 6.66 | 9.08 | 5.34 | 8.72 | 24.46 | 18.59 |
| Austria | *M* | 13.10 | 10.46 | 10.55 | 11.22 | 25.80 | 26.11 |
| | *n* | 30 | 30 | 18 | 18 | 30 | 18 |
| | *SD* | 6.87 | 8.62 | 5.96 | 8.29 | 24.24 | 24.64 |
| Total | *M* | 13.13 | 14.38 | 9.71 | 11.31 | 33.01 | 23.02 |
| | *n* | 67 | 67 | 32 | 32 | 66 | 34 |
| | *SD* | 6.70 | 9.50 | 5.69 | 8.34 | 25.07 | 21.93 |

| ANOVA (differences between Romania and Austria) | | | | | |
|---|---|---|---|---|---|
| | Sum of Squares | *df* | Mean Square | *F* | Sig. |
| T0 Severity | .064 | 1 | .064 | .001 | .970 |
| T0 Distress | 835.363 | 1 | 835.363 | 10.588 | .002 |
| T3 Severity | 28.810 | 1 | 28.810 | .886 | .354 |
| T3 Distress | .335 | 1 | .335 | .005 | .946 |
| T0 Severity X Distress | 2863.213 | 1 | 2863.213 | 4.823 | .032 |
| T3 Severity X Distress | 363.255 | 1 | 363.255 | .749 | .393 |

These differences could be explained by the characteristics of the two samples, in Romania the informal caregivers being over-represented while in Austria the formal caregivers are more numerous.

### Informal vs. formal caregivers

This interpretation is verified by differences in the average scores obtained by formal versus informal caregivers (see Table 22). However, these observed differences are not statistically significant, most probably due to the low number of participants.

Table 22: NPIQ average scores by caregiver type (informal vs formal)

| Caregiver type | | T0 Severity | T0 Distress | T3 Severity | T3 Distress | T0 Severity x Distress | T3 Severity x Distress |
|---|---|---|---|---|---|---|---|
| Informal | *M* | 13.10 | 16.13 | 10.64 | 13.52 | 36.36 | 26.841 |
| | *n* | 37 | 37 | 17 | 17 | 36 | 19 |
| | *SD* | 6.92 | 8.47 | 6.63 | 10.16 | 22.36 | 27.41 |
| Formal | *M* | 13.16 | 12.23 | 8.66 | 8.80 | 29.00 | 18.20 |
| | *n* | 30 | 30 | 15 | 15 | 30 | 15 |
| | *SD* | 6.53 | 10.37 | 4.38 | 4.82 | 27.82 | 11.10 |
| Total | *M* | 13.13 | 14.38 | 9.71 | 11.31 | 33.01 | 23.02 |
| | *n* | 67 | 67 | 32 | 32 | 66 | 34 |
| | *SD* | 6.70 | 9.50 | 5.69 | 8.34 | 25.07 | 21.93 |

Overall, the results indicate a decrease in both severity and distress scores for NPIQ. Unfortunately, not all differences have found to be significant due to the low number of participants, but the tendency indicated a positive effect of the SUCCESS intervention.

### 3.2.4 SELF-EFFICACY

The impact on the caregiver's self-efficacy was assessed a 5-item scale inspired by scales applied in previous research (Merrilees et al., 2018; Fortinsky et al., 2002; see D5.1) at T0, T1, T2 and T3, i.e. at baseline, after 1, after 3 and after 6 months.

For the scores obtained at the self-efficacy scale, an increase from T0 to T1 and T2 can be observed but between T0 and T3 the scores remain the same (see Table 23). Nevertheless, the mean differences were not found to be statistically significant when we performed t-test for paired samples.

Table 23: Self-efficacy average scores

| Self-efficacy | | *M* | *n* | *SD* | *SEM* |
|---|---|---|---|---|---|
| Pair 1<br>T0 vs. T1 | T0 | 3.69 | 40 | .72 | .11 |
| | T1 | 3.83 | 40 | .54 | .08 |
| Pair 2 | T0 | 3.69 | 37 | .68 | .11 |

| | | | | | |
|---|---|---|---|---|---|
| T0 vs. T1 | T2 | 3.78 | 37 | .59 | .09 |
| Pair 3<br>T0 vs. T3 | T0 | 3.72 | 33 | .59 | .10 |
| | T3 | 3.72 | 33 | .68 | .11 |
| Pair 4<br>T1 vs. T2 | T1 | 3.86 | 26 | .51 | .10 |
| | T2 | 3.73 | 26 | .57 | .11 |
| Pair 5<br>T1 vs. T3 | T1 | 3.79 | 28 | .56 | .10 |
| | T3 | 3.75 | 28 | .74 | .14 |
| Pair 6<br>T2 vs. T3 | T2 | 3.81 | 27 | .60 | .11 |
| | T3 | 3.74 | 27 | .66 | .12 |

### 3.2.5 KNOWLEDGE

The impact on dementia-related knowledge of the caregivers was assessed by applying a knowledge subscale applied in previous research (Karlin et al., 2017; see D5.1) at T0, T1, T2 and T3, i.e. at baseline, after 1, after 3 and after 6 months.

The average scores obtained at the self-assessment of the knowledge have increased from T0 to T1, T2 and T3. Differences between T0 and T3 are statistically significant at $p < .05$. In addition, also the increase between T2 and T3 is significant (see Table 24). Adjusting p-values with the Bonferroni method, only the difference between T0 and T3 remains significant. However, this procedure is conservative. On the one hand, the correction underlines the difference between T1 and T3 and thus, the longer-term effects on the perceived knowledge, on the other hand, the shorter-term increase, i.e. the increase from the baseline values to T2 and T3, should be tested with a larger sample to avoid false rejections of null hypothesis.

Table 24: Knowledge average scores

| | | *M* | *n* | *SD* | *SEM* |
|---|---|---|---|---|---|
| Pair 1 | T0_knowledge | 32.47 | 40 | 10.71 | 1.69 |
| | T1_knowledge | 35.82 | 40 | 10.75 | 1.69 |
| Pair 2 | T0_knowledge | 32.35 | 37 | 11.35 | 1.86 |
| | T2_knowledge | 35.21 | 37 | 10.22 | 1.68 |
| Pair 3 | T0_knowledge | 32.21 | 33 | 9.62 | 1.67 |
| | T3_knowledge | 37.81 | 33 | 8.66 | 1.50 |
| Pair 4 | T1_knowledge | 35.73 | 26 | 10.27 | 2.01 |
| | T2_knowledge | 35.30 | 26 | 10.89 | 2.13 |

| | | | | | |
|---|---|---|---|---|---|
| Pair 5 | T1_knowledge | 36.17 | 28 | 10.56 | 1.99 |
| | T3_knowledge | 38.42 | 28 | 8.86 | 1.67 |
| Pair 6 | T2_knowledge | 36.22 | 27 | 10.11 | 1.94 |
| | T3_knowledge | 38.62 | 27 | 9.27 | 1.78 |

| **Paired Samples Test** | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | **Paired Differences** | | | | | | | |
| | | | | **95% Confidence Interval of the Difference** | | | | |
| **Knowledge** | ***M*** | ***SD*** | ***SEM*** | **Lower** | **Upper** | ***t*** | ***df*** | **Sig. (2-tailed)** |
| Pair 1 (T0 – T1) | -3.35 | 8.26 | 1.30 | -5.99 | -.70 | -2.562 | 39 | .014 |
| Pair 2 (T0 – T2) | -2.86 | 9.34 | 1.53 | -5.98 | .25 | -1.865 | 36 | .070 |
| Pair 3 (T0 – T3) | -5.60 | 8.16 | 1.42 | -8.50 | -2.71 | -3.946 | 32 | .000 |
| Pair 4 (T1 – T2) | .42 | 5.04 | .98 | -1.61 | 2.46 | .428 | 25 | .673 |
| Pair 5 (T1 – T3) | -2.25 | 6.16 | 1.16 | -4.64 | .14 | -1.930 | 27 | .064 |
| Pair 6 (T2 – T3) | -2.40 | 5.93 | 1.14 | -4.75 | -.05 | -2.107 | 26 | .045 |

### 3.2.6 USER EXPERIENCE

The user experience of the SUCCESS app was assessed by applying the User Experience Questionnaire (UEQ) (see D5.1) at T1, T2 and T3, i.e. after 1, 3 and 6 months. The UEQ contains 6 scales with 26 items:

- **Attractiveness:** Overall impression of the product. Do users like or dislike it?

  Items: annoying/enjoyable, good/bad, unlikable/pleasing, unpleasant/pleasant, attractive/unattractive, friendly/unfriendly.

- **Perspicuity:** Is it easy to get familiar with the product?

  Items: not understandable/understandable, easy to learn/difficult to learn, complicated/easy, clear/confusing.

- **Efficiency**: Can users solve their tasks with the product without unnecessary effort?

  Items: fast/slow, inefficient/efficient, impractical/practical, organized/cluttered.

- **Dependability**: Does the user feel in control of the interaction?

  Items: unpredictable/predictable, obstructive/supportive, secure/not secure, meets expectations/does not meet expectations.

- **Stimulation**: Is it exciting and motivating to use the product?

  Items: valuable/inferior, boring/exiting, not interesting/interesting, motivating/demotivating.
- **Novelty**: Is the product innovative and creative?

  Items: creative/dull, inventive/conventional, usual/leading edge, conservative/innovative.

Attractiveness is a pure valence dimension. Perspicuity, Efficiency and Dependability are pragmatic quality aspects (goal-directed), while Stimulation and Novelty are hedonic quality aspects (not goal-directed). Figure 4 shows the assumed scale structure of the UEQ.

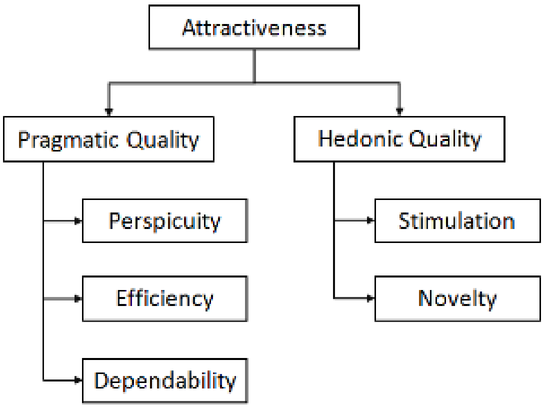

Figure 4: Scale structure of the User Experience Questionnaire (UEQ)

In general, scores below -0.8 are considered negative and scores above 0.8 are considered positive. Table 25 provides the scores obtained at the T1 assessment point (i.e. Perception of the App SUCCESS) and T2 assessment point (i.e. Perception of the SUCCESS avatar) and compares these scores with mean scores of a general benchmark (452 product evaluations) provided by the authors of the tool.

Table 25: UEQ average scores T1/T2 and benchmark

| UEQ scale | Benchmark | T1 assessment<br>Perception of the SUCCESS app | T2 assessment<br>Perception of the SUCCESS avatar |
|---|---|---|---|
| Attractiveness | 1.19 | 1.51 | 1.10 |
| Pragmatic Quality | | | |
| Perspicuity | 1.25 | 1.46 | 1.27 |
| Efficiency | 1.06 | .98 | .98 |
| Dependability | 1.15 | 1.35 | 1.04 |
| Hedonic Quality | | | |
| Stimulation | 1.01 | 1.78 | 1.20 |
| Novelty | 0.75 | 1.32 | .96 |

Results show that both, for the app and for the avatar the scores for all the scales are higher than 0.8 which indicates positive results. For 5 out of 6 scales of the UEQ completed by the study participants with the SUCCESS app in mind, scores are higher than the benchmark set for the “above average” category (categories are indicated in grey). For the avatar for three out of the six scales results are above the mean scores of the benchmark.

## 3.3 QUALITATIVE RESULTS

In addition to the quantitative results, main results of the final interviews in Austria are presented, as they provide additional insights on the perception and impact of SUCCESS in both target groups, formal and informal caregivers. In particular, results on the impact on the care routine and socio-economic aspects are important to attain a holistic picture of the impact of SUCCESS. An in-depth analysis of the qualitative results is planned as part of the publication of the study results.

### 3.3.1 GENERAL PERCEPTION

During the final interviews, users were asked to reflect on their initial expectations with regards to the SUCCESS app and, in order to get an insight on their general perception of the app, to imagine how they would describe the app to a friend or relative.

Austria

Asked about their initial expectations in the app, some participants stated that they had no specific expectations (*“no expectations, but curiosity if my answers will be answered”*; TP11, formal caregiver) or that they thought, *„that there could be a good idea behind it“* (#AT1, formal caregiver). Others expected the app to receive a similar information offer, *“as the one provided by the Alzheimer’s Association“* (#AT29, formal caregiver), *“to receive recommendations for various situations and problems related to the daily care routine”* (#AT35, informal caregiver) or *“support for difficulties in the everyday life with persons with dementia”* (#AT3, informal caregiver). Some participants stated that in the beginning, they were *“rather critical”* (#AT1, formal caregiver) and that had doubts whether *“using it would be too complicated”* (#AT11, formal caregiver). One formal caregiver (#AT18) stated that she was expecting that the app *“would be specifically for professional caregivers, providing tips and tricks and even advanced training for them”*.

Feedback on whether their expectations were fulfilled ranged from *“my expectations were fulfilled”* (#AT30, formal caregiver) to *“my expectations were pitched too high”* (#AT35, informal caregiver): One informal caregiver (#AT4) stated that she was positively surprised that the app *“not only works on content level but also targets emotional aspects”*. One formal caregiver (#AT18) commented that even she expected more advanced information for professional caregivers, for her *“it was good to refresh some knowledge”*.

When asked how they would describe the app to a friend or a relative, interviewees stated that *“SUCCESS provides a guideline for interacting with persons with dementia”* (#AT11, formal caregiver), that SUCCESS *“is a program that explains dementia and provides tutorials”* (#AT38, informal caregiver) and that *“in addition to information that is presented via articles and avatar lectures, in the background also says “take care of yourself” and provides respective recommendations”* (#AT29, formal caregiver).

### 3.3.2 USAGE TIME AND USER EXPERIENCE

One main part of the qualitative interviews focused on how participants perceived using the app in terms of time, motivation and the actual experience when using the app. This in particular includes the aspect of the perceived ease-of-use and feelings related to using the app.

Austria

**Usage time**

The exact number of days the participants were using the app over the six-month field trial ranges from 3 to 18 days. During this period, participants used the application SUCCESS between approximately 25 minutes and 9 hours. Next to the objective usage, we also asked the participants about their subjective usage time. The reported usage varied from every two weeks to every two months and from 20 minutes to 2 hours per usage. Some of the interviewees reported that they experienced a decreasing usage of the application SUCCESS: “*In the end less and less.”* (#AT37, formal caregiver), “*I used the app more at the beginning than I did at the end*.” (#AT30, formal caregiver), “*In the beginning very, very intensely.”*(#AT1, informal caregiver). Others, however, stated that they have used the app more towards the end than in the beginning, i.e., have experienced an incline in their usage time: “*Not so much at first, then more often*.” (#AT2, informal caregiver) and “*Of course I used less at the beginning, because it was not so easy* [to use]” (#AT15, formal caregiver). Moreover, the application was also used more intensely just after having received a reminder about the questionnaire (“*Whenever I got the reminder about a questionnaire, I used the app a bit more intensively again*.”; #AT7, informal caregiver). In the final interview some of the participants stated, that they would have liked to use the app more than they did (*“Unfortunately I did not have enough time to use the app as much as I wanted. I did not find enough time because of busy days at work and because of private commitments around Christmas. Sometimes I felt asleep while using my smartphone.”*; #AT16, formal caregiver). Multiple participants stated that they *“used the app in phases with less stress”* (#AT2, informal caregiver).

**User experience, acceptance and satisfaction**

Within the qualitative interviews, multiple aspects related to the User experience of the SUCCESS app, it’s acceptance among participants as well as their satisfaction with the solution were addressed. The following paragraphs provide a summary on the users’ motivation for using SUCCESS, the reported usage behavior, results related to the perceived ease-of-use and on hedonic aspects of using the system.

**Usage motivation:** Reflecting on the users’ motivation for using the SUCCESS app, during the interviews many participants stated that in the beginning, general interest and curiosity (mainly for the functionalities of the app) were the main drivers for using the system. Predominant reasons for using the app in later phases of the field trial were mainly related to the information provided by the system. For many participants, the main motivational factor was to reflect on the own behavior and on current reactions in specific situations that arise in the day-to-day life with a PwD: *“Is there something I could do differently? Am I right with my current actions?”* (#AT4, informal caregiver); *„I always used the app at home [i.e. not at work]. How can I do things differently the next time [a certain situation occurs at work].”* (#AT1, formal caregiver). In a similar way, one informal caregiver (#AT3) described that lack of knowledge was an important driver for using the system: *“Sometimes I used the app two days in a row. That happened when I had the feeling, that I should engage myself with the topic”*. In addition, also other participants mentioned the need for information on specific topics as reason for using the system: *"When it became obvious that this person would have to move into a nursing home soon, I had to check what are the possibilities"* (#AT4, informal caregiver); *"I mainly used the app when I needed inspiration for joint leisure time activities"* (#AT37, formal caregiver). In addition, also curiosity for newly added content was mentioned as reason for using the system: *"Sometimes I checked out of curiosity, if there is some new information provided"* (#AT3, informal caregiver). On the other hand, only one participant mentioned helplessness in acute situations as reason for using SUCCESS: *"I checked the app for information on specific situations, when I had lost my nerves."* (#AT3, informal caregiver).

**Perceived usage behavior:** In addition to the perceived user motivation, in the interviews participants were also asked to reflect on their actual usage behavior. Results show a clear shift in the perceived usage behavior from the beginning of the field trial to the later phases of the study: *"In the beginning I checked the app almost every day"* (#AT38, informal caregiver); *"At some point I had the impression that I had no more need for information. From this point on I used the app only to look up specific things"* (#AT11, formal caregiver); *"In the end I only looked up concrete questions"* (#AT27, formal caregiver). Other reasons for a changed usage behavior in later phases of the field trial were related to *"less clients with dementia"* (#AT11, formal caregiver) or changes related to the care situation: *"Initially I had a look at the app from time to time, but then I stopped, because my care situation changed a lot – which was very exhausting."* (#AT36, informal caregiver).

In general, the app was used for *"browsing the content"* (#AT11, formal caregiver) as well as in cases *"when it was needed"* (#AT13, formal caregiver). Many participants reported, that they used the app in less stressful moments: *"I used it in times of less stress at work, mainly in the evening"* (#AT16, formal caregiver); *"I used it on calm afternoons on the weekend to check multiple things at once – [active decision:] now I engage myself with the app for two hours"* (#AT18, formal caregiver); *"I used it before going to bed"* (#AT30, formal caregiver).

Asked about their usage behavior, many formal caregivers stated that they *"used the app mainly at home"* (#AT27, formal caregiver) because *"in addition to working with the clients, there is no time [for using the app] at work"* (#AT30, formal caregiver). One participant who provides mobile care services (#AT11) stated, that in difficult situations she left the client's living environment in order to check the app for guidance. Other formal caregivers said that they always used the app *"before visiting extreme clients"* (#AT13) or to be prepared for talks that they had to give (#AT29). Some participants could not use the app at work ("because I did not have the program on my work phone"; #AT16, formal caregiver) or did not use the app at work because they felt that this would be inappropriate: *"I wrote recommendations down on paper and then worked with them […] Some clients are afraid, if I start using the phone"* (#AT15, formal caregiver).

Related to the different media types provided by the app, participants stated that they had mainly read the articles (#AT11, formal caregiver), in order to *"address concrete questions"* (TP27, formal caregiver. Videos were used *"from time to time"* (#AT11) and *"more in the beginning"* (#AT27).

Some participants stopped using the app during the field trial *"because the app stopped working due to technical problems"* (#AT13, formal caregiver) or *"not because the app is bad, but because of my situation at work."* (#AT29, formal caregiver).

**Perceived ease-of-use:** Related to the perceived ease-of-use of the system, a majority of the participants stated that the app is *"very user-friendly – using the system was not a problem at all"* (#AT18, formal caregiver), the *"structure and [interface] design of the app is very clear"* (#AT1, formal caregiver) and that the app shows a good understandability: *"It was not hard to under-*

*stand"* (#AT27, formal caregiver). While some participants underlined that *"it is good to have a solution that allows you to look up certain topics whenever needed"* (#AT7, informal caregiver), others stated that they are not sure whether SUCCESS is the right solution for them because they are *"bad mobile phone users"* (#AT1, formal caregiver) or because they *"prefer talking to reading about things"* (#AT4, informal caregiver). In addition, also the need for personal support was raised: *"In the beginning it was not easy. But when someone showed me [how to use it], it was really interesting"* (#AT15, formal caregiver).

During the interviews some participants raised doubts, whether the approach of having the information and training offer on a smartphone is suitable for typical caregivers: *"The age is an issue: sometimes caregivers are older – therefore using the system has to be as easy as possible"* (#AT16, formal caregiver); *"The only problem is, that it only works on Android phones and not on a normal PC – older people need larger displays"* (#AT1, informal caregiver).

The roleplays and avatar lectures provided by the SUCCESS app were assessed differently by the participants. While some interviewees said that *"especially in the beginning [they] were disappointed by the avatars, because they did not really work [on their phones]"* (TP7, informal caregiver) other users stated that they appreciate this feature "because it is vivid and interactive – other than just reading an article" (#AT29, formal caregiver) and *"not bog-standard"* (DE: *"nicht null-acht-fünfzehn"*; TP30, formal caregiver). In addition, it was also recommended that there should be an "extra hint on the availability of the roleplays" (#AT1, formal caregiver) in the system.

**Emotional aspects:** During the final interviews participants were also actively encouraged to reflect on feelings related to the usage of the SUCCESS app. Some of the interviewees stated, that they did not have specific feelings while using the system: *"What kind of feelings? [Using the app] I refreshed my knowledge on specific topics. That's it."* (#AT3, informal caregiver); *„The app did not arouse feelings, but that's not negative at all."* (#AT36, informal caregiver). A majority of the participants could describe hedonic aspects, that they experienced when using the SUCCESS app. Many interviewees mentioned general positive emotions: "interest, fun – overall positive" (#AT29; formal caregiver). Reasons for these positive emotions vary between participants: *"the sheer availability [of the app] caused a good feeling"* (#AT11, formal caregiver); *"it is always a good feeling to have a look [into the app]"* (#AT3, informal caregiver). Multiple participants mentioned the continuous improvement of the app as reason for feelings of joy: *"I was delighted to see that the app was filled with additional information and that the roleplays suddenly worked on my phone – that was an aha-experience"* (#AT7, informal caregiver); *"my negative attitude in the beginning changed to a positive one because of these advancements"* (#AT36, informal caregiver). In addition, informal caregivers described that they had feelings of skepticism when they received the app: *"I was kind of skeptical. Why should I use this? I'm working [as a professional caregiver] for so many years – so I already know everything. But then I found out that I was wrong. There are many things that I had done wrong so far."* (#AT15, formal caregiver). Main reason for negative emotions related to the app were technical problems: *"Stupid diary! I was not able to scroll down, so it didn't work for me. That was frustrating!"* (#AT29, formal caregiver).

### 3.3.3 CARE ACTIVITIES

The use of the SUCCESS app had different effects for formal and informal caregivers. Statements of the participants regarding the perceived usefulness of the app, as well as changes in the care situation, care behavior, care activities and routines were extracted, thematically structured, and are summarized below.

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**Perceived usefulness for formal caregivers**

A majority of the formal caregivers involved in the field trial stated that for them SUCCESS was very useful (*"a very useful app that allows you to get targeted information"*; #AT1, formal caregiver). Positive aspects underlined by the participants were as follows: SUCCESS provides targeted information specifically relevant in the context of dementia; unlike many other (online) resources, SUCCESS is a trustworthy source for information and guidance (*"one can also have a look to the internet, but there you also find a lot of nonsense"*; #AT27, formal caregiver). While some formal caregivers stated, that *"there is information for all stages of dementia"* (#AT27), others stated that SUCCESS is more useful in early stages of dementia and that especially for later stages of dementia there is a lack of recommended activities - more ideas about that would be desirable. Some participants mentioned the understandability of the SUCCESS content as positive aspect of the app (*"very, very easy written and not professionally overblown"*; #AT11, formal caregiver)

**Situational support:** Lots of feedback of the formal caregivers focused on the benefit of SUCCESS as a tool that allows to learn about important aspects of dementia (*"it allows you to understand the disease, and it is important to develop an in-depth understanding [about it]"*; #AT18, formal caregiver) and as a tool that provides useful tips and guidance on how to deal with specific situations. Many participants underlined the value of SUCCESS as a tool that allows to get quick feedback on concrete questions: *"[in the working routine of a formal caregiver] it is not always the case, that there is someone that you can ask – [having SUCCESS] one is not alone in this case"* (#AT3, formal caregiver); *"put in a nutshell, one finds the necessary answers quickly, faster than in a book"* (#AT1, formal caregiver). One formal caregiver stated, that *"some topics were not very relevant for our work routine"* (#AT15). Furthermore, many participants stated that SUCCESS helps to refresh their knowledge about things learned in the past or to reflect on their current behavior: *"I thought that I know everything, but I learned a lot."* (#AT15, formal caregiver); *„[SUCCESS] tells you how to act in case of specific behavior, how to better handle it – aha, I could also act like this"* (#AT3, formal caregiver).

Related to the avatar-based content types (roleplays and lectures), some formal caregivers stated, that they appreciate the visual and interactive nature of these content elements (even when experiencing problems when interacting with the avatars): *"I did not really get along with the avatars […]. Some people prefer to see things [instead of reading about them], that's not bad."* (#AT10); *"Avatars are demonstrative and interactive, that's different from just reading articles"* (#AT27). Another formal caregiver stated that she liked *"to have questions that allow to test yourself"* (#AT18). The same participant criticized the roleplays because they over-simplify the behavior of people with dementia: *"A [virtual] actor cannot transport the behavior [of a person with dementia], [the avatar seems to be] too slow and stupid, bright moments are missing, that's not natural"* (#AT18).

Multiple participants stated, the they used SUCCESS specifically to inform themselves on behavior that they experience with specific clients (before, during or after visiting them). One participant came up with the idea to implement a *"diary [that allows you] to track and document situations related to specific clients together with reactions that worked – like this also colleagues could benefit from this"* (#AT16, formal caregiver).

**Activity recommendations:** During the final interviews, formal caregivers provided a lot of feedback on the activity recommendations provided by SUCCESS and came up with numerous ideas on how to align the content offer better with their personal needs. *"One gets recommendations on how to include the person with dementia, with sufficient patience. You have to pick them up, where they are. And you get reminded, not to work yourself up into it [if something works not out as planned]."* (#AT10, formal caregiver). Response from participants also showed, that not all recommendations work in every case: *"when viewing old photographs, she understood her current situation"* (#AT27, formal caregiver).

Feedback on missing content was mainly related to the constraints of the professional care routine: *"It would be good to have more tips on things that can be done at home, only with pen and paper, and things that can be done within 30 minutes. I tried to apply some things, […] but some things are too complex to do them within one hour [that I visit them]"*, *"simple things like puzzles with letters, also because for some people it's not easy to stay focused for a longer period of time"* (#AT27, formal caregiver"). In addition, formal caregivers stated that it is important that the app provides sufficient recommendations that can be implemented by caring relatives and proposed to include more tips for seasonal activities.

**Self-care:** Several participants highlighted the self-care features of SUCCESS as a very positive aspect: *"there could be more of that"* (#AT27, formal caregiver*); "Not long ago I watched the meditation video – this was a good reminder, that it is important to take care of myself"* (#AT27, formal caregiver). Another participant (#AT1, formal caregiver) questioned the value of the meditation videos *("Rather than meditation, this is yoga. For meditation it should not be necessary to look at the screen"*) and stressed the value of a real trainer (*"An instructor could answer questions and helps to relax even more. The problem is, that amateurs [performing meditation] tend to sit cramped"*).

Furthermore, participants underlined the value of interpersonal encounters: *"Despite good information, SUCCESS cannot replace the interpersonal aspect, sometimes one needs a shoulder to lean on"* (#AT16, formal caregiver); *"one should also get in touch with [self-help] groups and counseling services to stay in personal contact with others"* (#AT27, formal caregiver).

### Changes in care for formal caregivers

Formal caregivers participating in the field study reported different effects on the care situation, the perceived behavior of their clients as well as their professional activities and their personal well-being.

**Overall care situation:** The overall influence on the care situation seems to be heavily related to the individual care context of the participants. While some informal caregivers did not perceive specific changes related to care behavior, care activities and routines, others clearly stated, that because of SUCCESS they *"had an easier time at work and in private life"* (#AT16, formal caregiver) and that SUCCESS helped them to *"approach work challenges in an easier and less stressful way"* (#AT15, formal caregiver).

One formal caregiver working in mobile care (#AT15) reported that the information provided by SUCCESS supported a decision to extend the length of their visits to individual clients: *„So far we usually only had half an hour [at the home of the client]. […] I discussed this with colleagues in a meeting and told them that it improves the interaction with certain people a lot, if we do not have* *to stress that much. That's exactly what I read [in SUCCESS]. My colleagues agreed and now we do it like this. This is a big plus for the ones with severe dementia."*

**Impact on persons with dementia:** Reflecting on the influence on the perceived behavior of their clients, multiple participants reported that they could *"indeed apply the tips [provided by SUCCESS] in specific situations"* (#AT15, formal caregiver) with a positive impact on the interaction with the client: *"Thanks to the information [provided by SUCCESS], I'm now able to handle specific situations better. If something happens, one recalls tips read before"* (#AT16, formal caregiver); *"I have the impression that there was an impact of the app on me and on the clients because it made me sensitized."* (#AT11, formal caregiver); *"With some clients I'm no longer having problems that I had in the past"* (#AT15, formal caregiver). Asked about specific behavioral changes, participants stated that SUCCESS helped them to build awareness for the needs and wishes of their clients: *"I'm now posing questions differently by empathizing with their situation"* (#AT16, formal caregiver); *"I now try to get to the bottom of, what the person really wants."* (#AT16, formal caregiver).

During the final interviews, participants also mentioned very concrete strategies recommended by SUCCESS that helped them. Multiple participants for example mentioned that SUCCESS helped them to learn how to deal with aggression or to overcome the rejection of important activities: *"Some refuse to shower because they seem to be afraid of water. Here I could copy the strategy [proposed by SUCCESS] and since then it works. Awesome!"* (#AT15, formal caregiver); *"I have tried out tips from the app. This one person always refused to go to the doctor. Talking to her in the end made herself clear, that she should see a doctor"* (#AT16 , formal caregiver). Feedback from formal caregivers also showed, that not only acute problems led to the adaption of the communication and interaction with their clients: *"For situations like 'I want to go home' I understood that it is better not to lie to someone, but to draw off her attention to something else"* (#AT5, formal caregiver); *"The app has an impact because it reminds one that for example it is important that persons with dementia keep doing certain things themselves"* (#AT10, formal caregiver).

**Impact on caregivers:** In addition to the impact on the care situation and the behavior of their clients, also the impact on the care persons themselves was addressed within the final interviews. Most participants stated, that SUCCESS had some impact on their self-efficacy, the confidence in their own behavior as care person or on their overall well-being at work: *"Workwise the interaction with persons with dementia is now much easier for me. I'm now going to work with more calmness"* (#AT16, formal caregiver). Many participants underlined that they appreciate that SUCCESS *"tells you, that you also have to take care of yourself"* (#AT27, formal caregiver) and that it *"supports you to reflect upon yourself and how to deal with [difficult situations]"* (#AT11, formal caregiver). One formal caregiver stated that she does not need this feature: *"The app tells you 'take care of yourself'. In fact I don't need this, I'm strong. But maybe this is because I'm not a caring relative"* (#AT3, formal caregiver). Other participants stated that a conscious separation of professional responsibilities and private life and *"not taking things personally"* (#AT11, formal caregiver) helped them to *"become more resilient at work"* (#AT3, formal caregiver).

While one formal caregiver stated that for her SUCCESS did not have an influence on the self-confidence (#AT18), others stated that mainly due to *"strengthening and validating one's existing knowledge"* (#AT1, formal caregiver) the app improves confidence in the own abilities. One person reported a clear influence on her own self-efficacy: *"I thought that I know everything because I'm now working [as professional caregiver] for years. But I was wrong. […] Now I'm a better caregiver. Now I'm better, that's for sure."* (#AT15, formal caregiver).

During the final interviews many formal caregivers stated that more than as a tool for themselves, SUCCESS would be a *“a very useful tool for caring relatives […] as practical guide and additional support*” (#AT3, formal caregiver), *“especially if one has little or no experience to look up helpful tips”* (#AT10, formal caregiver). *“Lectures on dementia often do not reach this target group”*, thus SUCCESS *“could be of use for the main care person, but also help daughters/sons and grandchildren”* (#AT16, formal caregiver). The information is presented *“in clear language and without difficult words”* (#AT18, formal caregiver), *“[SUCCESS] covers many topics that could help relatives a lot, in all respects”* (#AT1, formal caregiver) and *“because it’s often too much for them, e.g. also meditation would be good [for them]”* (#AT27, formal caregiver).

**Perceived usefulness informal caregivers**

The feedback on the perceived usefulness of the app provided by informal caregivers was less heterogenous compared to formal caregivers. In general, also informal caregivers underlined that *“the idea of SUCCESS is great, it’s a tool with low-threshold”* (#AT7, informal caregiver), *“some kind of reference guide where you can look up a lot of information on how to deal with dementia”*, *“if there is no one else that you can ask”* (#AT2, informal caregiver), *“it’s something special – whenever I have some time left, I can look up things”* (TP38, informal caregiver). One participant stated that *“[SUCCESS] is useful if one is helpless, without any barrier you get access to professional support – especially in rural areas personal counseling is often connected to feelings of shame, that’s why it’s good!”*, *“the app provides quick access to the topic”* (#AT7, informal caregiver).

In addition to this overall positive feedback, feedback from the informal caregivers shows a clear pattern related to the usefulness of the app in relation to the existing experience of specific users. On the one hand, all participants underlined that *“the app is very useful if someone is new to the care responsibility, because the app provides comprehensive information on the topic of dementia”*; *“it is important to upfront get to know the disease, to know what is going to happen in the near future and how to deal with it – from my personal experience I can tell that in the beginning one is very helpless”* (#AT4, informal caregiver), . One participant stated: *“The app is fantastic! It helped me a lot during the first months in order to better understand the disease”* (#AT38, informal caregiver). On the other hand, many participants stated that the app is less useful for caregivers with a lot of existing experience, in case of later stages of dementia or in case of acute emergency situations: *“I’m now doing this for 8 years, there you have already experienced most situations”* (#AT4, informal caregiver), *“at some point caring relatives have more knowledge than provided by the app”*, *“there is too little information for later stages of dementia”* (#AT3, informal caregiver). One participant stated: *“In my case the care situation changed a lot which took me a lot of energy. In this situation the app cannot help anymore”* (#AT36, informal caregiver).

**Situational support:** Most informal caregivers stated that they appreciate, that SUCCESS provides information on how to deal with specific situations and behaviors they are confronted with in their daily care routine: *“SUCCESS was useful as a guide to check what is the best way to react in situations that did not occur before”* (#AT4, informal caregiver), *“things that I read in the app made me approach certain problems in a different way”*, *“SUCCESS taught me that changing the topic is sometimes better than always trying to correct [the person with dementia]”* (#AT38, informal caregiver). One participant demanded that – in addition to the information on specific situations – the app should provide more information on bureaucratic challenges related to the care responsibility: *“[…] how to deal with the authorities, where do I get an Euro key, what are my rights (what do I have to accept and what don’t I)?”* (#AT9, informal caregiver)

Related to the different content types and the multimodal approach of SUCCESS, it is noticeable that many informal caregivers stated that they liked that the app provides the possibility to read out the articles to them (#AT3, #AT4, #AT7). During the final interviews only a few informal caregivers provided dedicated feedback on the avatar-based content types. However, one participant (#AT3, informal caregiver) demanded a higher number of roleplays: *“Roleplays are good, because you see how you should interact. Unfortunately, there were only a few of them. Would be good to have more because they are very practice-oriented”*.

**Activity recommendations:** During the final interviews, not much feedback related to the activity recommendations was provided from the side of the informal caregivers. Only one participant (#AT35, informal caregiver) commented that the recommendations provided by the app *“are suitable for persons between 70 and 80 – but many persons with dementia are older”* and therefore demanded more content suitable for older people.

**Self-care:** Some participants stated that SUCCESS helped them to set their own limits and to allow more distance in case of conflicts: *“I learned to better deal with my situation [as a caregiver] by reducing conflicts, keeping the necessary distance and adapting communication”* (#AT2, informal caregiver), *“not taking things personal and ensuring oneself that you are not alone”* (#AT3, informal caregiver). However, one participant underlined that an app like SUCCESS “could never replace personal contact with experts, because only together with them one can reflect on the very individual situation” (#AT3, informal caregiver). In addition, one informal caregiver (#AT38) suggested to add information on how to deal with family conflicts that arise as consequence of a family members’ disease.

**Changes in care for informal caregivers**

Informal caregivers participating in the field study reported different effects on the care situation, the perceived behavior of the persons that they are caring for as well as their own care situation and their personal well-being.

**Overall care situation:** Compared to the formal caregivers, more informal caregivers reported that SUCCESS has no positive influence on their overall care situation: *“actually no changes”* (#AT7, informal caregiver), *“no, SUCCESS did not have an influence”*, *“I already knew many things before, SUCCESS did not change much”* (#AT35, informal caregiver). However, one participant stated: *“Unlike me, my husband did not engage himself with SUCCESS. He then noticed that in some situations I react differently than in other situations and that this works”* (#AT16, formal (and informal) caregiver).

**Impact on persons with dementia:** While some participants stated that *“the app provides many possible solutions [on how to deal with difficult situations]”* (#AT35, informal caregiver) and useful recommendations like *“that in many cases to draw the attention to something else in case that logical arguments don’t work”* (#AT3, informal caregiver), feedback from the final interviews does allow for a concluding assessment whether in informal care relations, SUCCESS has an impact on the persons with dementia themselves. Feedback from multiple participants suggests that the progression of the disease outweighs the positive impact of SUCCESS: *“The health situation of my mother went down steeply including a lot of physical aggression. SUCCESS could not change this.”* (#AT36, informal caregiver).

**Impact on caregivers:** In contrast to the impact on the person with dementia itself, feedback from the final interviews clearly showed that there is a positive impact on the informal caregivers in terms of confidence, self-efficacy and well-being. In general, participants stated that *“Thanks to* *the information [provided by SUCCESS], I'm now dealing better with certain situations. If something happens, I then recall the things that I have read before"* (#AT16, formal caregiver). Many participants underlined that SUCCESS either encouraged them, that their behavior is the right one or allowed them to adjust their behavior in order to improve the interaction or communication with their relative: *"The app contributed to affirm my existing knowledge. Things that I was not sure about were confirmed by well-founded information. Sometimes you are not sure, whether your assumptions are right – there the app helped."* (#AT3, informal caregiver), *"I frequently got encouraged in my behavior and also in my attitude towards the disease and regarding my relation to my mother. […] Whenever feelings of self-doubt arose, the app encouraged me."* (#AT35, informal caregiver). Other participants stated: *"I liked this aspect of the app a lot because also in my self-help group we talked a lot about the importance of taking care of oneself"* (#AT1, formal caregiver), *"the app opened my eyes, I then shared information from the app with my brothers"* (#AT38, informal caregiver).

One participant described that putting recommendations into practice is not an easy thing to do: *"I recognized that there are situations where I do not act properly. But changing things is emotionally challenging. […] To bring this from theory into practice is sometimes not easy. How can I teach the person, that she is not right? These situations generate stress. It is necessary to separate emotions and facts. Facts don't count for persons with dementia – they live in their own world. One can look up a lot on this [in SUCCESS]."* (#AT4, informal caregiver)

One formal caregiver (#AT1) mentioned that getting information on aspects of dementia that are not relevant in their specific care situation could also have negative effects: *"One might see things that they did not want to see."*

### 3.3.4 SOCIO-ECONOMIC IMPACT

In the final interview, interviewees were asked about the most suitable end-user; whether they would recommend the app if the receiver had to pay for it, and whether they felt healthier after having used the app. Based on the deductively coded categories target group, willingness to pay, sick leave, and recommendation to others, we inductively identified subcategories presented in the following sections:

Austria

**Target group**

The interviews show that the possible target group of the SUCCESS application is very diverse and broad. It includes professionals, informal caregivers, family, friends, and in general everybody who is in contact with a PwD. However, some interviewees stated that the application might rather be well-suited for a younger generation and technology-smart people.

For "professionals" interviewees mentioned, formal caregivers and people that have contact with PwD due to their job, e.g., people working in retirement and nursing homes. SUCCESS was found to be suitable for formal caregivers that are either in training ("*In nursing schools, something like this should be incorporated in the lessons*"; #AT16, formal caregiver), new in their profession ("*We have all started somewhere […] at the beginning of formal caregivers, one can always learn.*"; #AT18, formal caregiver), or in need of information on dementia ("*Caregivers who need some catching up in this area.*; #AT2, informal caregiver). With regards to formal caregivers, knowledgeable caregivers were not comprehended as a potential target group: "*Rather relatives, because* *nurses need to know more.*" (#AT5, informal caregiver). Apart from formal caregivers, it was reported that people dealing with PwD in their jobs might also be potential beneficiaries of SUCCESS, e.g., people working in retirement and nursing homes, in administration offices and as police officers. Hereby, one participant (#AT2, informal caregiver) stated: „*Anywhere you interact with people with dementia*".

Next to the category "professionals", the interviewees also reported informal caregivers, family, friends, and children as a potential target group of the SUCCESS application. Especially, informal caregivers were found to be the "perfect" end-users: "*Perfect for informal caregivers*" (#AT18, formal caregiver) and "*as an informal caregiver, one has to deal with the care 24/7; you need such an assistance*" (#AT27, formal caregiver). Hereby, it was also highlighted that the smaller the knowledge about dementia, the more suitable and beneficial SUCCESS might be: "*The less basic knowledge, the more interesting is the app*." (#AT35, informal caregiver) and "*Those who are newly confronted with the disease and do not yet have any knowledge. Even more in the private than professional sector since training courses are offered there*" (#AT10, formal caregiver). A possible target group was also identified in people who do not have access to self-help groups or want to have a further medium of instruction as "*In principle, it is like a self-help group with regards to the information content just presented differently - this is probably good if you have nothing in the neighborhood. Two approaches that are not mutually exclusive*." (#AT4, informal caregiver). However, the target group of SUCCESS is not solely restricted to informal caregivers, but generally comprises people who are close to the PwD: *"Family, brothers, friends, all people that are involved in the care of this person.*" (#AT38, informal caregiver) and everybody who is interested in learning something about dementia. Regarding the latter aspect, a participant could imagine the use of the application SUCCESS in dementia education in schools: "*I can even imagine this being used at school.*" (#AT4, informal caregiver).

Even though the suggested target group is rather broad, some individuals were not found as suitable end-users of the application SUCCESS. Firstly, people who do not own a smartphone or have trouble using one: "*Someone who has problems with cell phones can't do that*." (#AT15, formal caregiver). Secondly, people who are not fluent in German. Thirdly, people with extensive knowledge about dementia. This also includes formal caregivers and doctors. Fourthly, people with dementia themselves. One interviewee, however, imagined that a young PwD might be a suitable target group as "*Especially young PwD might also need information services*" (#AT16, formal caregiver).

In conclusion, it can be summarized that especially people who (in)formally care for or are in contact with PwD, but are not very knowledgeable about dementia yet, have been mentioned as a suiting target group. Based on the interviewees' suggestions, not part of that target group are people with dementia and people who do not own a smartphone or have troubles using it.

### Willingness to pay

Based on the qualitative interviews, the category willingness to pay has been aggregated into three subcategories: subscription type, amount, and prerequisites.

Subscriptions that were mentioned as being suitable for SUCCESS by the interviewees were: one-time, monthly, and yearly payments. Some interviewees preferred a one-time payment as "*subscriptions are awful*." (#TN7, informal caregiver). The monthly payment subscription was suggested as the most fitting subscription type for the SUCCESS application by the interviewees. Some of the explanations for this choice were: „ *because if I don't want it anymore or the patient dies.*"

(#TN5, informal caregiver) and *„rather monthly, because the payment always provides an impulse to use the app*" (#TN37, formal caregiver). Apart from the payment cycles, interviewees also mentioned that a demo version of the SUCCESS app would be beneficial: "*A demo version should be provided and then they [the potential consumers] should see whether the app works for them and depending on this decide whether they want it or not*" (#AT37, formal caregiver).

The interviewees were also asked to suggest an appropriate amount of money for the purchase of SUCCESS. Reference points mentioned were books and training programs. The amounts varied greatly depending on the suggested subscription type. For one-time payments, an amount of 9,90€ up to 50€. This was amount was justified by: "*It's complex to develop such a thing*" and "*It is not like others of its kind*." (#AT30, formal caregiver). Amounts ranging from 2€ to 100€ were found as appropriate for monthly payments. Hereby, the interviewees also stated that an amount of 2€ to 7€ is too low: "*1-2€ would be too low, because then one would not appreciate it [the application SUCCESS]*" (#AT5, informal caregiver). With regards to yearly payments, one interviewee found a price ranging from 150€ to 20€ as appropriate. A differentiation in the pricing of the app depending on the working status was also asked for: "*A difference in price whether someone is already in retirement or not*" (#AT16, formal caregiver).

Even though the interviewees would recommend the application SUCCESS even if this person had to pay for it in order to use it, it was also mentioned that some would only recommend the application SUCCESS after certain conditions were met. Conditions with regards to the app included: "*regular updates […] with sound* content" (#AT3, informal caregiver) and the correction of all errors ("*Before the app is subject to charge, all errors need to be corrected*"; #AT7, informal caregiver). Stated prerequisites regarding potential buyers were: no other access to information about dementia ("*In certain situations, yes. If I have no other option, then yes. If I get information for free, then rather no."; #AT4*, informal caregiver) and if it is perceived as useful ("*Yeah, if one can see that it's really helpful*."; #AT13, formal caregiver). One interviewee could not imagine to recommend the application SUCCESS to someone as "*people wouldn't pay* […]*people want to pay less.*" (#AT15, formal caregiver). Apart from recommending SUCCESS as a fee-based app, the interviewees claimed that they would recommend SUCCESS: "*I would certainly recommend it and say that this is a helpful tool*" (#AT13, formal caregiver) and "*If* [the person] *is really at the beginning, I would recommend it because it contains the essentials, for this it is perfect."* (#AT18, formal caregiver). One interviewee also stated that people will like to have applications like SUCCESS in the future: "*The trend is surely moving in the direction of many being willing to use such an application*." (TP16, formal caregiver).

### Sick Leave

With regards to the sick leave, two categories have been aggregated: impact and no impact. An impact of the application SUCCESS on the users' health has been reported in the final interview by some; others, however, did not experience any impact of SUCCESS.

It was stated that the application helped with dealing with the psychological burden of care and being more resilient: "*This psychological strain of how I deal with clients.[...] I know. By taking some things less personally. Or by reflecting more on myself: Phew, what's that now, how can I handle it better. By becoming more resilient; that it [the situation] is more on a professional and not on a personal level.*" (#AT15, formal caregiver). Some interviewees claimed that SUCCESS had no impact on their health and consequently on their sick leave. This missing impact was explained by already being resilient and taking care of themselves: "[SUCCESS] *had no influence on health,* *because self-care has also been preached by me in my self-help group*” (#AT1, informal caregiver). Some interviewees also stated that they had never been sick before: “*I've never been absent due to illness*.” (#AT29, formal caregiver).

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# ANNEX