Report on the end-users’ context and everyday life

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Work Package WP1: Requirement Analysis and Identification of User Scenarios
Task T1.2: Pre-study
Coordination Troyes University of Technology (UTT)
Contribution Vienna University of Technology (TUW)
University of Siegen (USI)
SOZIAL GLOBAL Aktiengesellschaft (SOGL)
SOPHIA Franken GmbH & Co KG (SOPHIA)
E-Seniors (ESE)
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Introduction

Following the aim described in the project, the consortium has decided to follow a User-Centred Design (UCD) process powered by ethnographically-informed studies (figure 1).

The present deliverable reports the work done in task 1.2 “Pre-Study”, part of the Work Package 1: “Requirement Analysis and Identification of User Scenarios”. It corresponds to the step “Understand Users” in figure 1 above.

T1.2 follows the work done in task 1.1 “Identification of End-Users” and reported in D1.1 “Selected End-Users”, and the T1.2 outcome enables us to begin with confidence the work for the T 1.3 (Identification of Use Cases).

Methodology

Techniques used for the pre-study

We have decided to combine different techniques to be able to understand deeply the daily practices of the informal caregivers we have recruited for this pre-study:

- Interviews with gatekeepers to collect some general information about the daily life and burden of the informal caregivers.
- Zarit Questionnaire (See Appendix 1 for the English version)
  - Developed by Steven H. Zarit (USA), the aim of this questionnaire is to assess the level of burden experienced by the principal caregivers of older persons with senile dementia and disabled persons (Zarit, Reever & Bach-Peterson, 1980).
- Profile Questionnaire (See Appendix 2 for the English version which has been adapted for each country)
  - Designed within the TOPIC project, the profile questionnaire seeks demographic information on both the informal carers (e.g. gender, age group, marital status, educational level, etc.) and the care receivers (e.g. gender, age group, medical conditions, etc.). The questionnaire also addresses the care situation that the
informal carers are currently undertaking, asking for information about the types of help they need and the ones that they receive.

- **Cultural Probes (See Appendix 3)**
  - Cultural probes offer a relatively unobtrusive way of providing insight into how technology could fit (and why it sometimes does not fit) into a particular home environment. The method includes open-ended and evocative activities for participants to pursue in their own time to help narrate and depict their lives to researchers and technology designers (Benyon, 2010: 162-163).

- **Shadowing Observations**
  - Shadowing is an active type of observation whereby the observer stays with the participants for a given period of time and follows them wherever they go, i.e., the observer becomes the shadow of the participants (the informal caregivers). This refers to the participatory observations in the Project Proposal (Czarniawska, 2007).

- **Interviews**
  - Semi-structure interview guide is elaborated based on inputs from the data collected during fieldwork and from the Zarit’s Questionnaire. The guide lists the issues that should be approached during the interview, and the interviews should cover all the issues congregated in the interview guide.

- **Thematic Data Analysis**
  - Thematic analysis is an exploratory approach to data analysis in which themes are identified from the data and are coded according to what the analyst judges relevant to the emergent themes (Schwandt, 2007). It slightly differs from a content analysis a, in that it requires the reintegration and connection of the empirical themes with the source data, and from a grounded theory analysis approach, in that it is a data reduction and analysis strategy which aims at capturing the important concept within a data set and does not requires the development of a theory (Given, 2008; Gibson and Brown, 2009).

**Process**

WPI partners have collectively defined the following process. However, according to the diversity among participants, we have slightly adapted the process when needed, following the dynamics of a UCD process that allows for some flexibility as to when and what methods should be applied for its different phases. For instance, in some families, we have started the observations before distributing the cultural probes’ kit.

1. Application of the Zarit’s Questionnaire
2. Distribution of the Cultural Probe kits
3. Performing observations
   - Schedule: once every 15 days for each participant (informal caregiver). A total of 3 sessions of observation have been performed per participant over the period of 2 months (twice in the first month, once early in the second month of the phase).
   - Duration: each session lasted for about 3 hours.
4. Performing in depth semi-structure interview after the last shadowing session
5. Thematic data analysis of fieldwork data.
Results of the Thematic Data Analysis

Communication difficulties between the informal carer and the care receiver
From our observations, it is becoming more and more evident that communication difficulties between the informal carer and the care receiver due to different reasons (e.g. varied impairment that either informal carers or care receivers – or both – experience; some sorts of impairment combined with long distance care; etc.) are one possible source of stress for informal carers. Providing some sort of support to improve their communication may reduce some of the stress stemming from the care work.

Difficulties to be mobile whilst caring for someone
As the pre-study progressed, participants recurrently mentioned that sometimes they need or want to engage in short distance mobility (e.g. going outside to take care of some household chores, going to the bakery that is just on the corner to buy some fresh bread) but they feel concerned about what could happen with the care receiver during the short period of time when they are out. In cases which the care receivers are only slightly impaired, informal carers mention that care receivers could reach through mobile phones, however there is some ambivalence associated with this possibility, as they mention that sometimes they could miss a call or not realise that a SMS arrived or, in the worst case scenario, the incident with the care receiver may be more serious and prevent them to try to contact the former. Providing effective communication channels by using simple multimodal communication patterns combined with sensors to monitor the care receiver could contribute to alleviating informal carers’ preoccupation when they are not close to the care receiver.

Need for multimodal interaction mechanisms
The pre-study data yield findings showing that there are many variables impacting upon the activities in which informal carers and care receivers may (want to) engage in. Depending on the impairment of the users, time and place of use, complexity of interaction, emergency and safety issues, and different interaction mechanisms need to be provided through the technological developments designed for the different types of support to be offered for informal carers.

Being alone together
This theme describes observed situations in which informal carers were together with the care receivers, but did/could not interact with them. These situations could contribute to the feeling of being alone, which can lead to the development of a depressive condition. Providing tools that allows informal carers to connect with other people in order to interact and to escape this loneliness could be beneficial for informal carers.

Support for active participation
From the observations, it became apparent that informal carers are willing to engage in assorted types of activities (e.g. teaching people handcraft, putting together and managing a reading group, etc.). Giving them such opportunities can potentially make them to feel useful and also contribute towards reducing the different types of burden stemming from care work. Besides, taking part to a group appears also as a resource for them to find the motivation to do activities outside their home. For instance at the scale of a local day care service, some the family caregivers we met mentioned that they have done picnics during summer; they went to the bowling and invited each...
other for dinner. They coordinated to join yoga and dance courses offered by other local respite care services.

**Coping with time/event management**

This theme is strongly coming out of our data as is noticeable from the observations that informal carers usually have to juggle different things from the personal and care dimensions of their lives and keep track of different things in terms of the care they provide (e.g. medication, doctors’ appointment, etc.). This can add a layer of stress to their care work. Tools like a tangible calendar could potentially support informal carers in this regard.

**Monitoring the progress of care receiver’s or carer’s condition**

One recurrent remark coming from the fieldwork participants is that it would be interesting if they could easily keep track of the progression or regression of the care receivers’ condition. Additionally, proving they sometimes also experience some medical condition, they also would like to be able to keep track of their own health in a way that they take proper actions in time and look for help when they feel it necessary.

**Managing external help**

Our data show that, it is common for informal carers to get external help (e.g. from Heimhilfe). However, they cannot directly contact the people coming to their house to help and sometimes this could lead to some stressful situations (e.g. when the Heimhelfer(in) is late and they cannot say if they are close or distant from their place). Some of the care organizations provide a „time-window“ and not the correct time in which the carers will come, because of delays due to the public transport or problems with other customers (e.g. they need the ambulance). The informal carers are so deeply involved in caring and overburdened that they often do not use their presence for themselves but assist the carers in doing their work.

**Fearing the future without the care receiver**

This is another theme coming strongly from the data. Participants recurrently acknowledge that they cannot imagine their lives without their beloved ones. The platform could feature some “space” where informal carers could share their fears or talk with people who have already gone through the loss of a beloved person, making them prepared to cope with the situation in the future.

**Developing relationships with persons sharing a similar situation**

Some of the participants find support in participating support groups and having the opportunity to meet other informal caregivers. In this case, we identify some dimensions they considered as important for sharing a similar situation: the pathology, the relationship with the care receiver (being a child, a spouse, a parent …), the age.

**Sharing experiences and problems**

The time shared with other informal caregivers is an opportunity to talk about the daily problems they encounter in caring for their ailing relative to persons who can understand their situation. They provide advices to each other on how to deal with the care they provide. If nobody has been confronted to a situation, they discuss to try finding possible solutions.
Looking for activities to do with the care receiver
Some of the participants are desperately looking for activities that they can do with their ailing relatives. These activities can lower the burden because their relative is occupied and at the same time help them finding new interaction modes. This is especially true for spouses who are just retired and have envisioned their retirement as a leisure time together. They have then to adapt their dream to this new situation.

Sharing the burden with peers
For some of the participants, leaving their ailing relative in a day care service is in fact a source of stress (ie, will she/he stay calm? Would she/he not feel neglected if I leave her/him there?). This is especially true for spouses which means that putting distance between caregivers and their ailing relative may work against providing support. An alternative is for some of the participants to take part into collective activities (a walk in the forest, a picnic …) with other people in the same situation which they met in the day care service they are involved in. The distributed watch over provided by the group makes possible for informal caregivers to enjoy the moment and then to lower the burden while staying with their ailing relative.

Further work
The observations made during T1.2 and the themes revealed in this deliverable will allow us to elaborate Personas and Use Cases (T1.3). A meeting is planned (Jan. 15-16) among WP1 and WP2 partners to work on these Use Cases, focusing on feasibility and prioritization. It will lead to the starting of T2.3 (prototype development) and T4.1 (Preparation of Evaluation).

References


# Appendices

## 1. Zarit Questionnaire (English version)

Please circle the response the best describes how you feel.

<table>
<thead>
<tr>
<th>Question</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Quite Frequently</th>
<th>Nearly Always</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Do you feel that your relative asks for more help than he/she needs?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>2. Do you feel that because of the time you spend with your relative you don’t have enough time for yourself?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>4. Do you feel embarrassed over your relative’s behaviour?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>5. Do you feel angry when you are around your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>6. Do you feel that your relative currently affects our relationships with other family members or friends in a negative way?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>7. Are you afraid what the future holds for your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>8. Do you feel your relative is dependent on you?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>9. Do you feel strained when you are around your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>10. Do you feel your health has suffered because of your involvement with your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>11. Do you feel that you don’t have as much privacy as you would like because of your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>12. Do you feel that your social life has suffered because you are caring for your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>13. Do you feel uncomfortable about having friends over because of your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>14. Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15. Do you feel that you don’t have enough money to take care of your relative in</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
addition to the rest of your expenses?

16. Do you feel that you will be unable to take care of your relative much longer?

17. Do you feel you have lost control of your life since your relative’s illness?

18. Do you wish you could leave the care of your relative to someone else?

19. Do you feel uncertain about what to do about your relative?

20. Do you feel you should be doing more for your relative?

21. Do you feel you could do a better job in caring for your relative?

22. Overall, how burdened do you feel in caring for your relative?

| Total Score (out of 88) |

**Interpretation of Score:**

0 – 21 little or no burden
21 – 40 mild to moderate burden
41 – 60 moderate
61 – 88 severe burden

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2. Profile Questionnaire (English version – adapted for each country according to the care system)

TOPIC - Questionnaire V1.1 (When the participant refuses to answer a question please write >NA< in front of it)

Date: ....................

Step 1 – Background Information:

Information about the informal caregiver:

Surname: ........................................... First name: ...........................................

Gender: ☐ Male ☐ Female

Year of birth: ........................................... Marital status: ............................................

Educational level: ..............................................................

Employment status: ☐ not employed ☐ employed ................. hours per week

☐ self-employed

Profession: ..............................................................

Relationship with care receiver (family/friend)..............................................................

Guardian by law: ☐ yes ☐ no

Dwelling

I live together with the care receiver in the same household? ☐ yes ☐ no
I have a self-contained room in the flat? ☐ yes ☐ no
I have my own flat in the house? ☐ yes ☐ no
I live in the same location? ☐ yes ☐ no
The Online Platform for Informal Caregivers

**Limitations:**

<table>
<thead>
<tr>
<th>Category</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mobility</td>
<td>□ full mobile □ partly mobile □ not mobile</td>
</tr>
<tr>
<td>Hearing capacity</td>
<td>□ not impaired □ partly impaired □ heavy impaired □ fully impaired</td>
</tr>
<tr>
<td>Vision</td>
<td>□ not impaired □ partly impaired □ heavy impaired □ fully impaired</td>
</tr>
<tr>
<td>Familiarity with technology</td>
<td>□ familiar □ partly □ not familiar □ unknown</td>
</tr>
</tbody>
</table>

**Information about the care receiver:**

Surname: .................................................. First name: ..................................................

Gender: □ male □ female

Date of birth: day: ........................ month: .................. year: ........................

Level of care: □ none □ requested □ 0 □ 1 □ 2 □ 3

**Medical conditions:**

<table>
<thead>
<tr>
<th>Type</th>
<th>□ chronic □ acute □ evolving</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mobility</td>
<td>□ full mobile □ partly mobile □ not mobile</td>
</tr>
</tbody>
</table>
| Eye impairment        | □ cataract □ glaucoma
                       | □ blindness □ residual eyesight: _____% |
| Hearing impairment    | □ partially impaired □ deafness |
| Heart / circulatory disorder | □ cardiac arrhythmias □ cardiac insufficiency |
                       | □ high blood pressure □ heart attack □ stroke |
| Musculoskeletal system| □ limp □ arthrosis □ rheumatism |
The Online Platform for Informal Caregivers

- □ osteoporosis  □ multiple sclerosis  □ danger of fall
- □ amputation  □ protheses

Lung condition  □ chronic obstructive pulmonary disease (COPD)
- □ chronic bronchitis  □ asthma

Other conditions  □ Parkinson’s disease  □ dementia
- □ lack of coordination  □ diabetes
- □ speech impediment  □ permanent bedridden
- □ obesity  □ cancer

Therapeutic appliances  □ wheeled walker  □ wheelchair  □ bath lift  □ glasses
- □ cane / crutches  □ oxygen device  □ nursing bed
- □ hearing aid  □ others: _____________________________

Severe disability with proof:  yes □  no □

Disability level:  □ G  □ aG  □ B  □ RF  □ H  □ BL  degree in %:  __________

Step 2 – Care situation:

Since when are you an informal caregiver?

For: □ _____ weeks □ ______ months □ 1 year □ 2 year □ longer

Additional services

Mobile nursing service present: □ yes □ no

□ daily □ weekly □ 14-day □ monthly amount of hours:____________

Help from other members of the household: □ yes □ no

□ daily □ weekly □ quarterly □ monthly amount of hours:__________
What does the care receiver need help for?

- housekeeping (washing, cleaning)
- financial affairs and visits to the authorities
- shopping
- body care
- cooking
- eating
- going to and getting out of bed
- putting on clothes
- going to the toilet
- medication intake
- others, e.g. _______________________________________________________

Does the care receiver obtain any type of care benefit?

- yes  
- no

Which kind: __________________________________________________________
3. Cultural Probe Kit

The Cultural Probe kits designed for the Pre-Study included the following artefacts:

1. One set with **14 pictures** related to assorted care situations and use of technology.
2. One **diary notebook**, for participants to report on the activities that the engaged in during the probe period.
3. One **instant camera** for the to register any situation that they think would help the researchers to understand their daily life and give information on things that could help them with it or make it more enjoyable.
4. One set with two **packs of film** for the instant camera.
5. One **glue stick** for the participants to fix the pictures that they took in the diary notebook.
6. Two sets of assorted **markers**, for participant to draw or highlight things in the diary notebook and use for the analogue clock.
7. One set of **analogue paper clocks** for participant to map the types of activities they mostly performed in each of the 24 hours of the day they were reporting on and how they mostly felt during each of these hours.
8. One box of **emoticon stickers** for the clocks and the diary.
9. One **colour legend sheet** for participant to tell us the types of activity that you are reporting on the *analogue paper clocks*.
10. One **information sheet** explaining which emotion each smile face provide represented.
11. One **social map sheet**, which we would like you to use to tell us about the names of some people you talk with, the frequency and your relationship with them.

![Figure 2 TUW Cultural Probe Kit](image-url)
Figure 3 UTT and ESE Cultural Probe Kit
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