Seeing the World through the Eyes of Informal Caregivers with Cultural Probes

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Abstract

To get to know your target group is a very important first step in research projects – especially when they don't have enough time to tell you everything, like informal caregivers. During our pre-study in the project TOPIC we applied cultural probes combined with in-depth interviews and participatory observations. We asked the users to use a diary, Polaroid camera, *actimoClock*, emoticons, social map, and picture cards for a period of 14 days. Most of these cultural probes worked well and delivered important information about users' daily life, problems and feelings, while some were anticipated differently. The paper presents the cultural probes and their use by discussing some relevant findings.

1 Introduction

An informal caregiver is defined as a person who is providing permanent help and care that is unpaid (Hörl et al., 2008). This work is not based on a contractual basis and is not acquisitive. Their typical activities are personal activities of daily living (PADL) like body care, instrumental activities of daily living (IADL) like housework but also social activities like talking to them and spending time with them (Schneider et al., 2009).

In the European Union the majority of care work is done by informal caregivers (United Nations Population Fund, 2014). Their daily life can be described as interplay between routine work, spontaneous interruptions and lack of time (Schinkinger & Tellioğlu. 2014). Therefore, most of their time is heteronomous. Activities, decisions, emotions and/or finances of informal caregivers can often be in a relationship of dependence with their care receiver (Tellioğlu et al., 2014). Due to these facts, most of the informal caregivers are suffering from physical and emotional burden like mental overload, hopelessness, back pain, etc. (Pochobradsky et al., 2005; Winkler et al., 2006).

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Within the project TOPIC[1] we applied various ethnographic methods like participatory observations, in-depth interviews as well as cultural probes to analyse and understand the life situation of informal caregivers (blinded). This allowed us to develop technological solutions that can be integrated easily in the existing daily life of informal caregivers and should bring relief in their recurring tasks.

2 Cultural Probes in the Context of Informal Care

Within our pre-study of our informal caregivers, we offered them a box with several cultural probes and asked them to use the items for a period of 14 days.

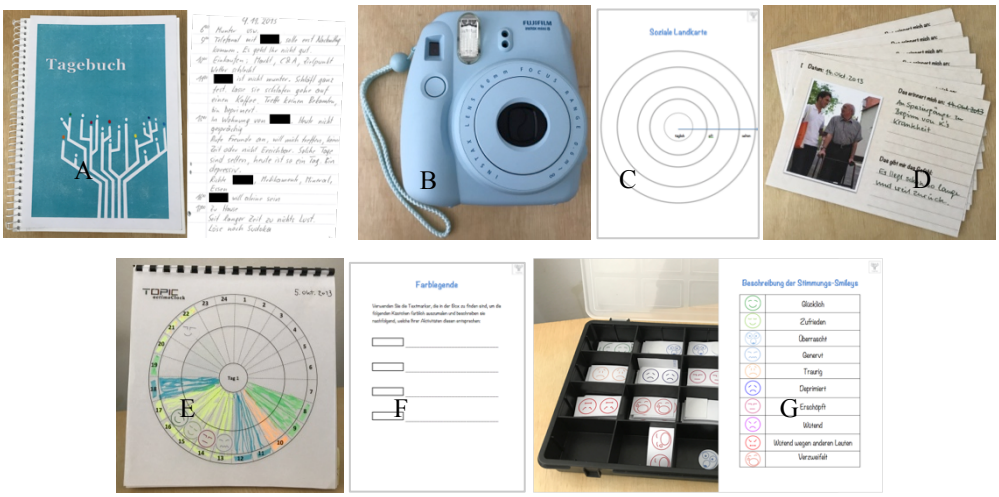

Figure 1: Items of the box with cultural probes: A) diary; B) Polaroid camera; C) social map; D) picture cards; E) actimoClock; F) colour legend; G) emoticons

The *diary* (A) was an ordinary notepad in the size of A5. We suggested that users in our project should write on a daily basis about: what their day was like, which tasks they carried out, which places they visited (e.g., park, supermarket, doctor's practice, …), which problems they had to deal with, with whom they had contact during the day, etc.

By using a *Polaroid camera* (B) the users were asked to take photos of situations during the day that they think are important, special, nice, burdensome, etc. These photos could be added to the corresponding diary entry to illustrate and evidence the written words.

The *social map* (C) should be filled out at the end of the 14 days' period. It should show with which persons the informal caregiver had contact during this time, how frequent this contact

[1] TOPIC – The Online Platform for Informal Caregivers, www.topic-aal.eu

was, and the relation to this person (e.g., family, friends, doctor,…). We also added 14 *picture cards* (D) to the box, which showed various situations in a care context. We asked the users to take a closer look at the photos and write next to it their thoughts and feelings with possible reasons.

The *actimoClock*[2] (E) was an item of the cultural probes kit that was specially designed by us for our target group of informal caregivers: With *actimoClock* it should be possible to illustrate the activities and their duration on a daily base. Therefore, it shows a clock with 24 hours where the tasks can be visualised with different colours. The activities and also their assigned colours were selected by the informal caregivers themselves and were defined in the *colour legend* (F). Moreover, we provided a set of *emoticons* (G). To show their mood or mood change during the day, the informal caregivers could add the smiley sticker to the *actimoClock*. To offer them the possibility to create a new emoticon with a mood that was not offered by our predefined emoticons, we added some blank stickers in the box.

3 Discussion

Combining interviews with the analysis of the data captured in cultural probes we gained insights about our users and their life situation that we discuss in this section.

Writing into the diary was well accepted by most of the users. Some wrote about their daily schedule, some detailed their feelings and some wrote just keywords about the highlights of their day (Figure 2). Two users really loved to write the diary because

> *"It was for me a little bit like writing it off my chest. It was like a therapy."*

> *"Writing the diary is also a distraction … to me at least."*

Several found it time-consuming:

> *"My husband said that I am spending a lot of time on the diary."*

> *"No, it wasn't difficult but sometimes time-consuming. […] You have to sit down and […] and say 'I am not here right now'."*

For a few users, it was hard or not possible to write anything down:

> *"To be honest, I didn't write anything. I took it once but didn't wrote anything."*

> *"Yes, I did not write that much in it. During the Christmas holidays I am more stressed than when the child is not here."*

Diaries told us a lot about our users (Mattelmäki, 2002). Users were free to decide when, where and how long to use them. A positive effect was that they were not observed, no bias

[2] actimo = ACtivity, TIme, MOod

at all by an observing researcher (Carter & Mankoff, 2005). Our users liked it when the photos were immediately developed by the Polaroid camera. Some even wanted to keep these photos for themselves. Photos they took informed us about important artefacts and situations occurred that we referred to during the interviews.

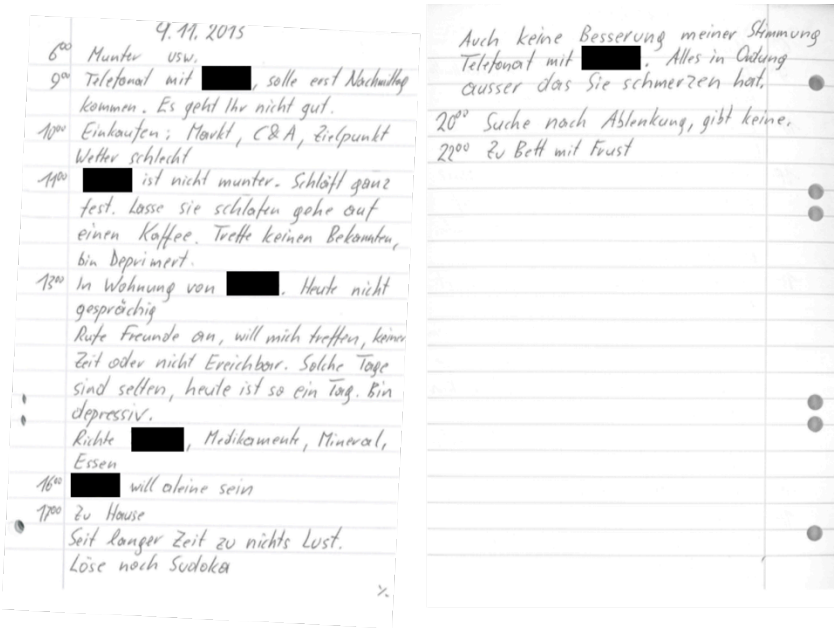

Figure 2: Diary entry of one of our informal caregivers in the project

Most of the users came along with the *actimoClock*. So, we were able to collect useful insights into their daily life (Figure 3). Two user pointed out that it would be useful to have smaller time slots than an hour for an activity. A few users complained that they were not able to fill the *actimoClock* because either they didn't understand it or it irritated them. One user realised while doing it that he is now spending less time at his care receivers' place. While for some users filling in the *actimoClock* was just a duplication of work because they already wrote their daily schedule into the diary, for others it was a good addition. Categories they used, activities they described, schedules they entered were very similar among the users. E.g. the three most commonly created categories for the actimoClock were unsurprisingly care, household and free time. Our users felt that their feelings were easily communicated by using emoticons showing the related tasks or situations in the clock. In combination with the diary, we were able to identify special circumstances that caused the mood swings of our users.

Emoticons worked well, both for the *actimoClock* and for the diary. Almost half of our users (4 out of 10) created their own emoticons, e.g., to visualise "I am tensed up" or "I am stressed".

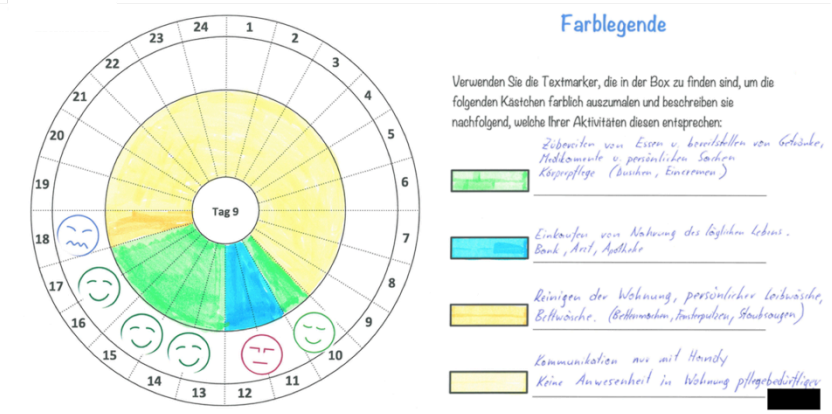

Figure 3: Example of the actimoClock and its corresponding colour legend

Despite the short introduction while handing over, it was not clear to some of the users how to fill in the social map. This leads to the fact that the social map was filled in by only 6 out of 10 users. Its self-reflecting functionality was perceived by some as unpleasant. Some were surprised how less contacts they actually had and to their surprise some others pointed out that they had more contacts than they have assumed. Social maps gave us only in rare cases additional information about the social environment of the informal caregiver, which was not already discussed before in interviews or informal talks.

The least response was to the picture cards: Most of the users didn't fill them in. The majority pointed out that some of the pictures did not create any emotion by them:

> *"I was not doing it because I didn't have any connotation to it."*

> *"It says nothing. The first picture tells something but the others are not relevant."*

Picture cards were not the right way to confront the users with different care situations including such that were new to them. But during the final interview the (non-)reaction to the cards gave us the possibility to have a hook for going on with the interview and to address some questions we were still interested in.

4 Conclusion

Cultural probes are useful tools to gain an insight into the daily life and circumstances of the targeted user group (Connelly et al., 2014). Particular in the case of informal caregivers because this is a world you never want to enter or to follow up with until you are suddenly part of it. They enrich the data material of ethnographic research because they deliver information that is usually not possible to get with just asking questions (Deswbury et al., 2003). They work best when they are combined with other ethnographic methods like in-depth interviews and participatory observations (Kriglstein & Wallner, 2005). When working with busy users, cultural probes need to be self-explanatory and easy-to-fill-in. They can be applied at the

beginning and at the end of a research project to relate the findings and the impact of the deployed systems.

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