Data-Driven Infographics for Counseling Interviews with Family Caregivers in Dementia Care

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Abstract

Family caregivers for persons with dementia are under a lot of physical and emotional strain. To alleviate their needs, the Angehörigendialog provides a questionnaire and a handout report that mobile nurses use as guide for counseling interviews with family caregivers. This work presents a follow-up project, in which we designed and implemented a web-based questionnaire and bespoke data-driven infographics for the report. The tool was created in a human-centered design process in cooperation between researchers in visualization and social work sciences. Target users were involved in focus group interviews in the beginning and finalization of the project. The resulting infographics designs are, on the one hand, robust regarding the possible inputs that care givers can provide in the questionnaire. On the other hand, they apply metaphors to be easily understandable and motivate a resource-oriented reflection. The Angehörigendialog is a case study at the intersection of personal and collaborative data visualization. It engages a visualization scenario with data at a tiny, personal scale that is visualized for personal reflection and to support mutual communication in the counseling interviews.

Keywords

Data Visualization, Health and Social Care, Social Diagnostics, Human-Computer Interaction,

1. Introduction

Dementia affects an increasing number of people. Worldwide, there were over 55 million persons with dementia in 2020 [1] and an estimated 147 000 persons lived in Austria with dementia in 2018, which are 1.66% of the population [2]. Dementia is a cognitive disorder caused by several diseases that affect memory and thinking. As dementia progressively impairs activities of daily living, a high level of care is needed, which is very often provided by family members or other informal caregivers [3, 4]. These family caregivers often feel overwhelmed as they need to manage care tasks in addition to jobs, child care, or other obligations. On top of that, caring for a family member is both physically and emotionally exhausting [3].

The *Angehörigendialog* [5] is a social-diagnostic instrument that was developed to identify and alleviate the needs of family caregivers in the Austrian region of Burgenland. It provides a questionnaire that mobile nurses use as guide for counseling interviews with family caregivers. The answers are summarized in a handout report for the caregiver. In a follow-up session, they reflect the situation based on the handout and discuss coping strategies as well as external support offers. The main focus of this work are the bespoke infographics that have been designed in the scope of the digitalization of the questionnaire used for the Angehörigendialog. In addition, some technical aspects of the web-based solution are demonstrated. This work addresses visualization challenges to, on the one hand, encourage a resource-oriented reflection by caregivers and, on the other hand, provide robust visual output for user inputs of varying extent and completeness.

It is structured as follows: Section 2 provides information about the original questionnaire design for the Angehörigendialog and its previous implementation. Then, Section 3 describes the process and methods of our redesign and digitalization project. In Section 4, we present four of the infographics in

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Figure 1: Process of applying the two artifacts of the Angehörigendialog: the questionnaire guides the first counseling session between the family caregiver and a mobile nurse; the handout report is given to the caregiver and is reflected together in the second counseling session.

detail and contextualize them with their design rationale. Finally, Section 5 outlines technical implementation aspects of the digitalization project and Section 6 reflects on the work from a visualization perspective.

2. Previous Work on the Angehörigendialog

The work reported here builds on top of the original *Angehörigendialog,* which is a socio-diagnostic instrument for conducting counseling interviews to strengthen the resources of family caregivers [5]. It was developed in 2016 by the Ilse Arlt Institute for Social Inclusion Research in cooperation with Volkshilfe, which is a large Austrian non-profit, non-governmental organization offering social services. In 2018, the instrument was evaluated in a study that involved the counseling of 76 family caregivers in a rural area of Burgenland, Austria.

The Angehörigendialog [5] involves two counseling sessions between the family caregiver and a mobile nurse and two artifacts (Figure 1): a questionnaire and a report. In the first session they discuss the individual situation of the caregiver, their burdens, and their resources. This session is guided by a *semi-structured questionnaire,* which was designed specifically for such interviews with family or informal caregivers for persons with dementia.[1] The questionnaire includes extensive textual guidance for the mobile nurse so that the counseling sessions can be conducted without special psychological training. For example, a list of 167 resource-providing activities, based on a list by Lammers [6], is given to caregivers who cannot name resource-providing activities on their own. After the first counseling session, a *handout report* with visualizations of the individual answers is handed over to the caregiver and a second appointment is scheduled. Then, the answers on the caregiver's situation are reflected together so that coping strategies and available support can be discussed.

When the Angehörigendialog was originally developed, it was realized as a paper questionnaire of 12 pages. To create the handout, the nurses had to transcribe the answer into the cells of a MS Excel spreadsheet. Then the spreadsheet automatically produced a four-page report containing simple infographics (Figure 2). However, this transcription process was criticized as cumbersome and error-prone. Therefore, we started a follow-up project in 2020 to redesign the artifacts for the Angehörigendialog as a fully digital solution. In the course of the redesign, we focused on sophisticated infographics in particular.

3. Methods

The redesigned Angehörigendialog was created in a human-centered design process by a mixed team of researchers in visualization and social work sciences. Two focus group interviews in the beginning and the finalization of the project brought in the perspective of target users. Three domain experts from the Volkshilfe organization (two female, one male) participated in the first interview in April 2020. The second interview in September 2020 involved an additional domain expert (three female, one male). Both

[1]The complete questionnaire can be consulted in the report of the previous project [5] or in a demo of the redesigned Angehörigendialog (https://angehoerigendialog.fhstp.ac.at/).

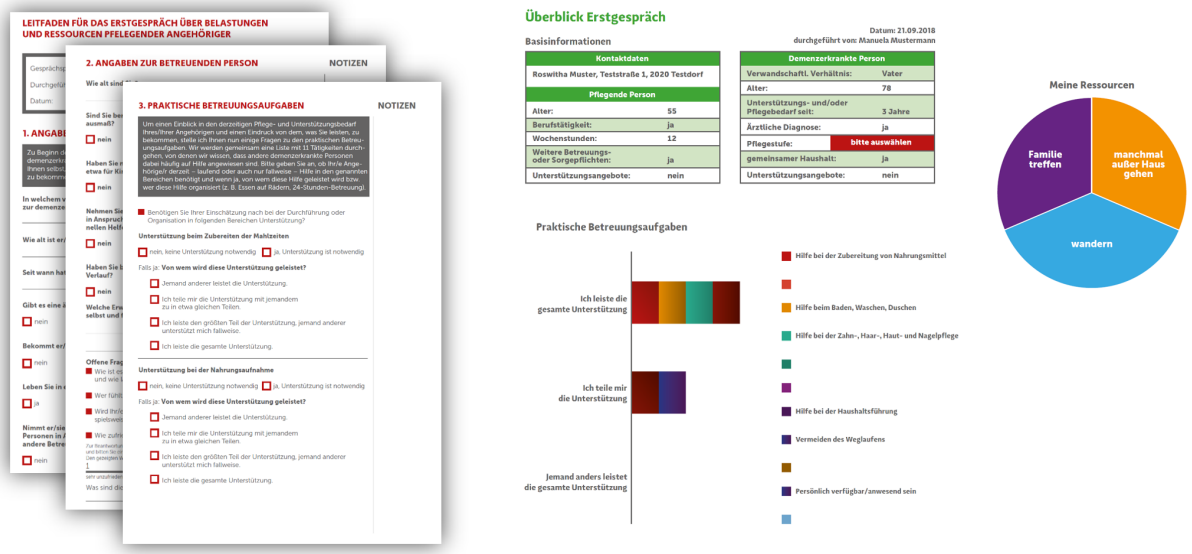

Figure 2: Paper-based questionnaire of the original Angehörigendialog and exemplary parts of the Excel-generated handout report

focus group interviews were held as online meetings over Zoom. In the initial problem characterization stage, we performed data analysis and abstraction of the questionnaire items, state-of-the art research in visualization idioms and infographics suitable for health information (e.g., [7, 8, 9, 10, 11]) and the first focus group interview. Resulting from this stage, the design goals were as follows:

- to provide an efficient web-based tool for mobile devices (in particular tablets),
- to replicate the structure and the wording of the paper questionnaire,
- to visually encourage reflection focusing on resources instead of deficits,
- to make the infographics robust regarding possible inputs and missing information, and
- to perform all data processing and storage locally on the used device.

We created sketches for the infographics using the Five Design Sheets methodology [12] and iteratively designed wireframes and mockups for the web interface to the questionnaire. Both were implemented using the web development framework vue.js while iteratively considering feedback from social work, user experience, and visualization experts in the team. The second focus group interview allowed formative evaluation of the web-based questionnaire and the infographics with external domain experts. The next section will focus on the feedback received from them and how it was addressed in the final infographics.

4. Data-Driven Infographics

The redesigned handout report has a length of four pages containing a block of basic information about the caregiver and five infographic blocks.

The first infographic block is headed with “I have time for”. It covers how caregivers experience personal limitations as a result of the care and support tasks. This is determined by presenting six statements, such as “I have enough time for my hobbies and interests.”, and asking whether these statements apply to their individual situation on a three-level scale. Our sketching converged on the metaphor of a flower that blooms if the caregiver agrees to have enough time and withers if they disagree. A watering can symbolizes the need for self-care and aims to give a resource-oriented perspective on the situation. The design iteration presented at the second focus group interview depicted a schematic flower with six petals that each represent agreement to one of the six statements by color (Figure 3). A minimal color scheme of blue, red, and grey was used throughout the handout report at this iteration.

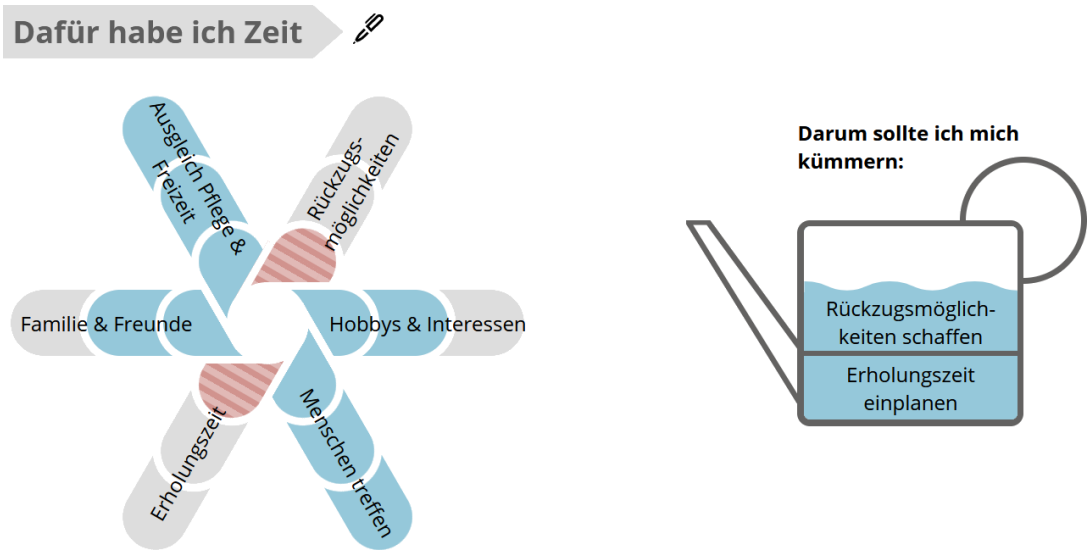

Figure 3: Infographic on the caregiver's time (design iteration before the focus group interview).

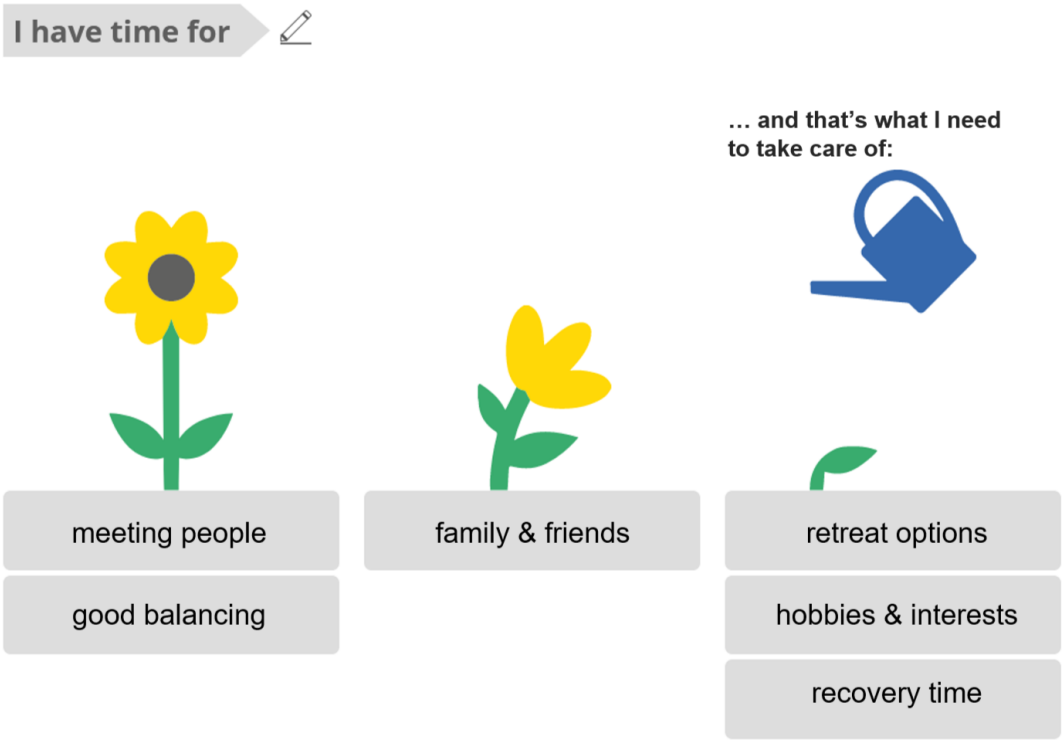

Figure 4: Infographic on the caregiver's time (final design, translated to English).

The watering can would grow in size or disappear depending on the number of statements that the caregiver had disagreed to have time for. The domain experts appreciated the metaphor of watering a flower, but they criticized that this design was too abstract to be recognizable as a flower. The blue color was not interpreted as positive, and the diagonal labels were hard to read. Furthermore, they had the impression that the infographic puts too little focus on what works well. Consequently, we redesigned this block to make it more realistic. The final design presents up to three flower beds for the agreement levels: the first with a tall blooming flower, the second with a half-grown flower, and the third with a sprouting plant and a watering can (Figure 4). The questionnaire statements are spatially arranged below the corresponding flower resembling a raised bed. If an agreement level was not present, its flower bed would be hidden. The design can use more colors without making it unusable for readers

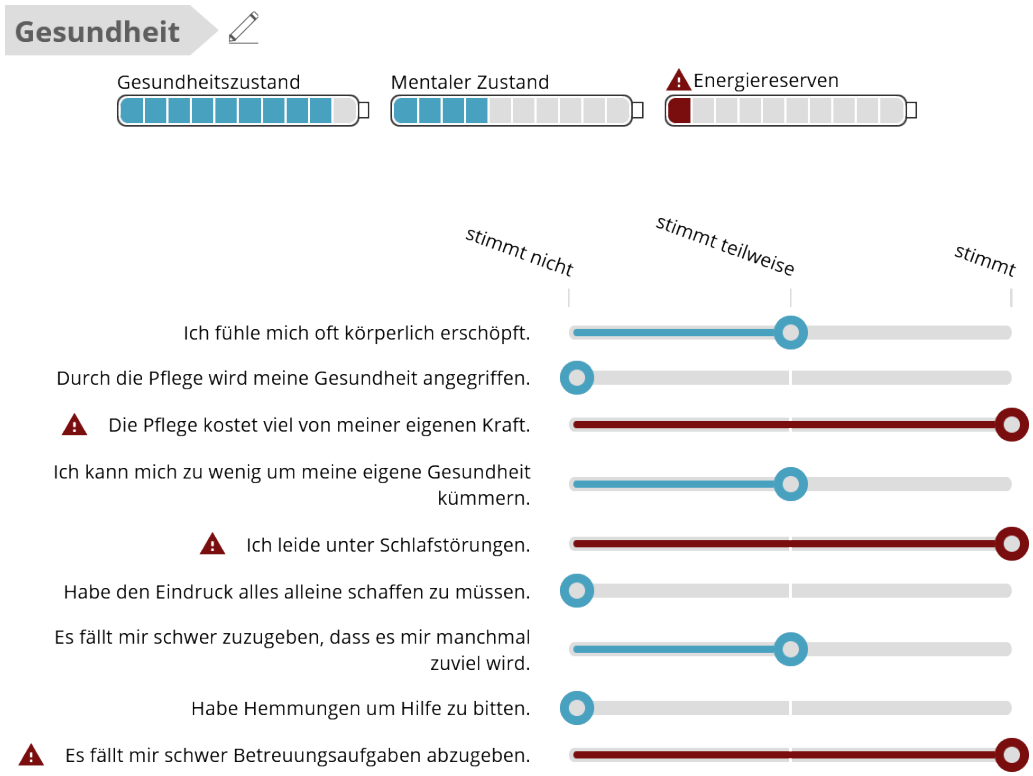

Figure 5: Infographics on the caregiver's health (final design).

with color blindness. To provide a positive perspective, even the plant for disagreement is depicted in green – though with a smaller area.

The next two infographic blocks are concerned with how well the caregiver copes with behavior change and about their health status. Both blocks represent answers to items on a Likert scale and are depicted as lollipop charts with blue and red color coding (Figure 5). In addition, the health block, contained three battery icons that acted as bar charts. These blocks were well understood by the domain experts and did not require another design iteration.

Practical care tasks are the topic of the fourth block. The questionnaire lists 11 activities where persons with dementia could need support (e.g., preparing meals, prevent falls) and collects if that support is needed and who provides that support. Does the caregiver provide it completely, does someone else provide partial support, is it shared with someone else, or is someone else providing the support. This provides an opportunity to discuss additional regional support offers such as meals on wheels. In the infographic (Figure 6), these activities are depicted as boxes that are arranged spatially into four columns. Each column is carried either by one or by two persons and a text label describes the category. The focus group interview resulted in minor refinement to make the persons representing the caregiver recognizable using the color yellow and the label "ICH" on their torso. The same design is repeated in the block with basic information about the caregiver. Yellow is used to represent the caregiver, while green indicates external support.

The final infographic block addresses personal resources and burdens. These questionnaire items are answered as free text. An arbitrary number of text boxes is provided for entry of resources, while the burdens are limited to maximum three. The answers for resources are depicted inside a hot-air balloon, while the burdens are shown as weights below the basket (Figure 7). The domain experts found the metaphor easy to understand and generally a good concluding block for the handout report. Yet, it was also mentioned that the metaphor of flying could be uncomfortable for persons with fear of heights.

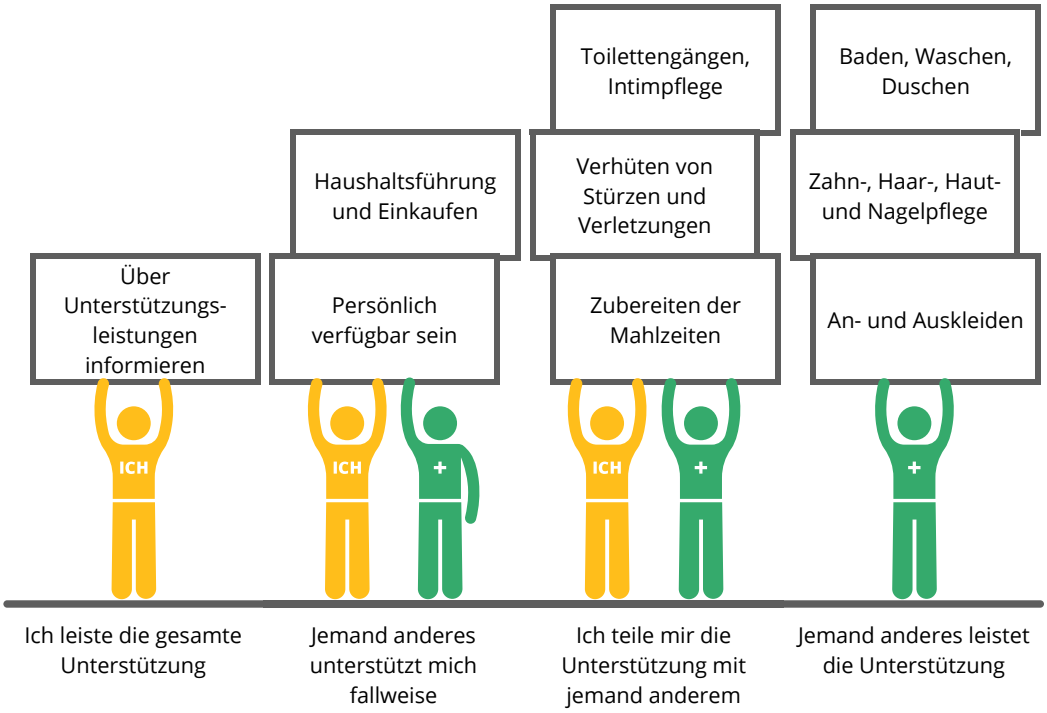

Figure 6: Infographic on tasks shouldered and support received from others (final design). One activity is supported by the family caregiver alone; for two activities there is occasional support by someone else; three activities' support is shared; and three activities are supported by others. The person with dementia does not need support in two activities, which are, therefore, not shown in the infographic.

5. Technical Aspects

The web-based questionnaire (Figure 8) comprises the complete text of the previous paper version including all interview guideline texts. It is structured into ten thematic sections with a representative icon and a checkmark indicating whether all questions have been answered Answering and navigating the questionnaire is possible with mouse, keyboard, and touch for good user experience across different notebook and tablet setups. In addition, free-text note-taking is possible in all sections of the questionnaire.

The Volkshilfe organization asked for a web application so that it runs on different platforms and does not require an installation process. Since the purpose of data collection is limited to the two counseling interviews, it is sufficient to process the data within the web browser and clear it afterwards. Finally, the domain experts emphasized that the web application needs to work in remote rural locations without Internet access. Therefore, it was set up as a progressive web application. For customizability, the questionnaire's structure and text are defined in YAML format. The individual infographics are realized as vue.js components. The software and the designs are available as free and open-source software at https://github.com/fhstp/angehoerigendialog.

6. Conclusion

The *Angehörigendialog* is an insightful case study for a visualization scenario for personal reflection and to support communication in the counseling interviews. Its characteristics are distinct from the visualization scenarios typical in exploratory data analysis:

- Rather than big data with thousands or millions of items, this scenario visualizes a *single data item,* the caregiver's personal data. This resulted in a software architecture without the need for a central database, a server infrastructure, or data protection strategies.

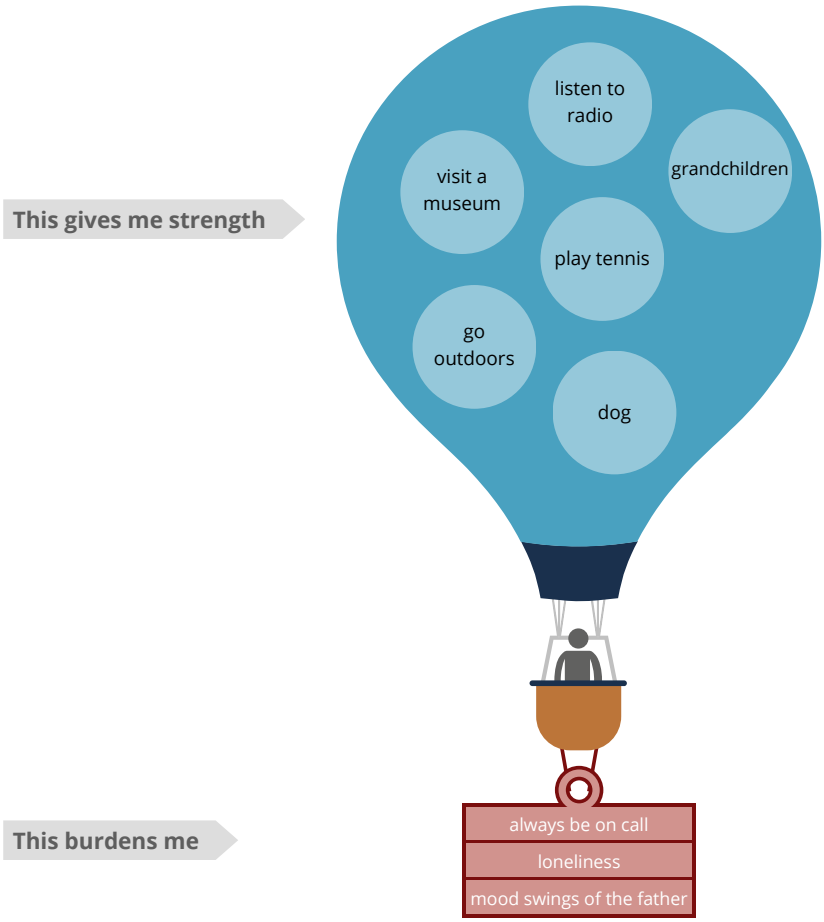

Figure 7: Infographic on personal resources and burdens (final design, translated to English)

- Rather than summarization or comparison tasks, it needs to support *reflection* and *communication* based on the principles of social-diagnostic work [13].
- Rather than focusing on deficits, the infographics need to provide an encouraging, *resource-oriented perspective* that promote caregivers' self-determination.
- Rather than minimalistic aesthetics, relatable and *understandable metaphors* are needed. This is best illustrated on how the "flower" metaphor was redesigned from an abstract star-shaped graphic (Figure 3) to pictorial flower beds (Figure 4).

Thus, the redesign of Angehörigendialog marks the intersection of the fields of social diagnostics [13], collaborative data visualization [14], and personal visualization [15].

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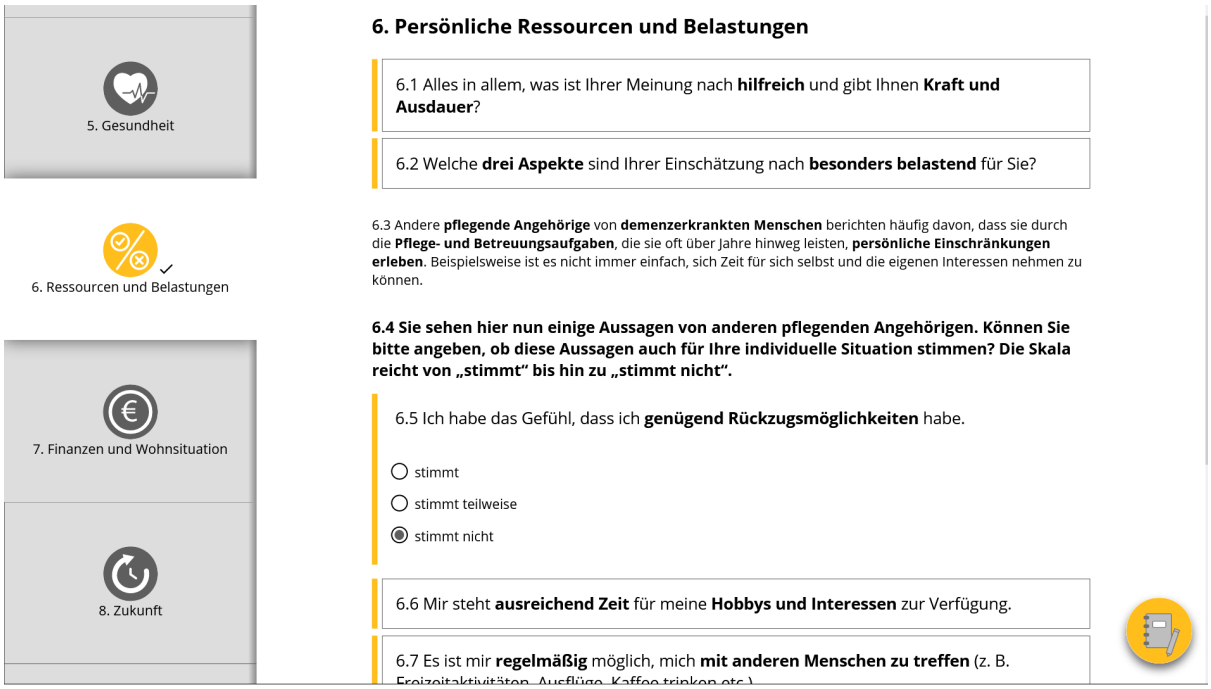

Figure 8: Data entry questionnaire section on resources, burdens, and personal limitations.

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