

# Enhancing Support Ecosystems and Assistive Technologies for Family Caregivers of Individuals with Dementia in Austria

# A Comprehensive Analysis & Improvement Suggestions

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# **DIPLOMA THESIS**

submitted in partial fulfillment of the requirements for the degree of

# **Diplom-Ingenieurin**

in

## Media and Human-Centered Computing

by

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# Erklärung zur Verfassung der Arbeit

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Wien, 18. September 2024

Viktoria Schweitzer



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# Kurzfassung

Laut dem österreichischen Demenzbericht sind etwa 115.000 bis 130.000 Menschen in Österreich von verschiedenen Formen der Demenz betroffen. Angesichts der alternden Bevölkerung wird erwartet, dass sich diese Zahl bis 2050 verdoppelt. Obwohl bemerkenswerte Fortschritte bei assistiven Technologien erzielt wurden, sind diese Lösungen hauptsächlich auf Patienten ausgerichtet, wodurch die zentrale Rolle der Pflegepersonen, insbesondere pflegender Angehöriger, unbeabsichtigt in den Hintergrund gedrängt wird.

Pflegende Angehörige, die Zielgruppe dieser Studie, müssen oft Pflegeverantwortung mit ihren eigenen Vollzeitbeschäftigungen vereinbaren. Zudem erleben zahlreiche Familien eine Aberkennung staatlich finanzierter professioneller Pflege, wodurch ihre finanziellen und physischen Ressourcen eingeschränkt werden. Angesichts dieser Rahmenbedingungen geraten pflegende Angehörige in eine verstärkte soziale Isolation und Unsichtbarkeit, was zusätzlich zu den berichteten emotionalen Belastungen, technologischen Defiziten und rechtlichen Herausforderungen beiträgt.

Zur umfassenden Analyse der Bedürfnisse pflegender Angehöriger in Österreich wurde in der vorliegenden Forschung angestrebt, die aktuelle Situation dieser Zielgruppe zu untersuchen, bestehende Unterstützungsangebote kritisch zu evaluieren und die Rolle sowie Präsenz der Technologie im Pflegebereich systematisch zu bewerten. Darüber hinaus wurden potenzielle Bereiche für technologische Verbesserungen identifiziert. Dabei wurden die Präferenzen pflegender Angehöriger berücksichtigt, einschließlich eines hypothetischen Szenarios, in dem Technologie aufgrund der sensiblen Natur der Pflegerolle möglicherweise nicht erwünscht ist.

Zur Untermauerung dieser Erkenntnisse wurden Informationen aus aktuellen Forschungsprojekten, Literaturrecherchen und Interviews mit Experten sowie pflegenden Angehörigen in Österreich herangezogen. Anschließend wurde ein Design Thinking Workshop durchgeführt, an dem pflegende Angehörige sowie ausgewählte Interessengruppen teilnahmen, um realistische Ideen und konkrete Anforderungen für potenzielle zukünftige Technologien und Konzepte gemeinsam zu entwickeln.

Die Ergebnisse des Workshops identifizierten mehrere Bereiche, in denen eine potenzielle Integration von Technologie sowohl als wünschenswert als auch als nützlich angesehen wurde. Dazu gehörten Lösungen zur Steigerung der Effizienz organisatorischer Alltagsbelange durch rollenbasierte digitale Kalender und To-do-Listen. Zudem wurde der Bedarf an einer zentralisierten digitalen Wissensbasis für Unterstützungsangebote und Vernetzungsmöglichkeiten artikuliert. Zusätzlich wurde die Entwicklung digitaler Leitfäden für Anträge auf Pflegegeld sowie eines gebündelten Informationspakets vorgeschlagen, um unerfahrene Pflegepersonen in ihren ersten Schritten als Pflegekraft zu unterstützen.

Angesichts der Komplexität der Ergebnisse konzentrierte sich die Studie anschließend auf die Weiterentwicklung von Lösungskonzepten für digitale Kalender. Dieser Fokus wurde gezielt eingegrenzt, um ein qualitatives Ergebnis sicherzustellen. Im Zuge dieser Eingrenzung wurde ein nutzerzentrierter Anwendungsfall mit funktionalen Anforderungen für potenzielle assistive Technologien entwickelt. Abschließend wird empfohlen, die Validierung dieses Anwendungsfalls und der funktionalen Anforderungen mit den Studienteilnehmer\_innen sowie weiteren pflegenden Angehörigen und Interessengruppen durchzuführen. Darüber hinaus wird eine umfassende Untersuchung der Ergebnisse der verschiedenen Fokusgruppen des Design Thinking Workshops empfohlen, um weitere technische Lösungsvorschläge zu konzipieren.

Zusammenfassend deutet die Studie auf die Notwendigkeit einer optimierten Integration von Technologie hin, da jüngere, technikaffine Generationen zunehmend mit der wachsenden Prävalenz von Demenz konfrontiert werden und möglicherweise Pflegeaufgaben selbst übernehmen müssen. Trotz des derzeitigen Mangels an technologischen Lösungen deuten die Ergebnisse auf eine Offenheit der untersuchten Zielgruppe gegenüber neuen Technologien hin. Die Teilnahmebereitschaft am Design Thinking Workshop und die aktive Mitgestaltung waren entscheidend, um die Bedürfnisse adäquat zu erfassen. Somit wird die Bedeutung der Einbeziehung von Nutzerfeedback in die Entwicklung zukünftiger Technologien unterstrichen und als effizientes Werkzeug für künftige Forschungsprojekte empfohlen.

# Abstract

According to the Austrian Dementia Report, an estimated 115,000 to 130,000 people suffer from various forms of dementia in Austria. Given the aging population, this number is expected to double by 2050. Although there have been remarkable advances in Assistive Technologies, solutions are mainly tailored to patients, unintentionally overshadowing the central role of caregivers, particularly family caregivers.

Family caregivers, the study's primary focus, often juggle caregiving responsibilities alongside their own full-time work obligations. Furthermore, the lack of eligibility for state-financed professional care leaves many families without adequate financial and physical resources, intensifying the reported social isolation and invisibility, emotional strain, technological deficits, and legal challenges, among others.

Hence, the present research aimed to explore the state of family caregivers in Austria, examine existing support structures, and assess the role of technology in the caregiving landscape. It also sought to identify potential areas for technological improvement while respecting caregivers' preferences, including the hypothetical scenario where technology might be undesired due to the sensitive nature of the caregiving role.

To support these findings, information was gathered through current research projects, literature reviews, and interviews with experts and individuals with lived experiences in Austria. A design thinking workshop was subsequently conducted, involving family caregivers and selected stakeholders, to co-design realistic ideas and requirements for potential future technologies and concepts.

The findings of the workshop revealed several areas where technology was both desired and beneficial. These included solutions for enhancing the efficiency of everyday task management through role-based digital calendars. It also highlighted the need for a comprehensive, digital single source of support structures and networking opportunities. Additionally, the development of digital guides for care allowance applications and a bundled information package was proposed to support new caregivers in their initial caregiving journey.

Given the complexity of the findings, the study next concentrated on investigating solutions for digital calendars. This focus was intentionally narrowed to ensure a qualitative outcome, resulting in the development of a user-centered use case accompanied by functional requirements for potential Assistive Technologies. Future work suggested by the study includes validating these proposed concepts with study participants or further family caregivers, and stakeholders. Furthermore, an extensive exploration of outcomes from the distinct focus groups within the Design Thinking Workshop is recommended.

In summary, the study underscored the urgent need for effective technology integration, as younger, tech-savvy generations will increasingly face the rising prevalence of dementia and may assume caregiving roles. Despite the current deficit in technological solutions, the research revealed a positive receptiveness among the target group toward new technologies. The willingness of participants to engage in co-design workshops was instrumental in ensuring that their needs and perspectives were comprehensively addressed, thus underscoring the importance of incorporating user feedback into the development of future technologies.

# Contents

Kurzfassung				
$\mathbf{A}$	Abstract			
Contents				
1	Introduction			
	1.1	Motivation and Problem Statement	2	
	1.2	Aim of the Work	3	
	1.3	Structure of the Work	5	
	1.4	Methodological Approach	8	
<b>2</b>	State of the Art			
	2.1	Family Caregivers of People with Dementia in Austria	16	
	2.2	Current Support Structures in Austria	19	
	2.3	Assistive Technologies for Family Caregivers in Austria	23	
	2.4	Concise Recap of Major Challenges Faced by Family Caregivers of People		
		with Dementia in Austria: Emphasizing Research Relevance	30	
3	The	Voice of Family Caregivers and Experts	33	
	3.1	Introduction	34	
	3.2	Methodological Framework for the Interviews	36	
	3.3	Interview Findings and Discussion	40	
	3.4	Conclusion	56	
<b>4</b>	Design Thinking Workshop			
	4.1	Introduction	62	
	4.2	Methodological Framework for the Workshop	64	
	4.3	Workshop Structure and Execution	69	
	4.4	Workshop Findings and Discussion	76	
	4.5	Conclusion	93	
<b>5</b>	Use	Case Development for User-Centered Design Concepts	97	
	5.1	Introduction	98	

xv

	$5.2 \\ 5.3$	Methodological Framework for Use Case Development Optimizing Informal Caregiving through Tailored Digital Calendar Solu-	100	
	5.4	tions	101 107	
6	<b>Disc</b> 6.1 6.2 6.3	cussion and Conclusion      Research Outcomes in Overview      Ethical Measures      Limitations and Prospects for Future Work	<b>109</b> 109 112 113	
Overview of Generative AI Tools Used				
ÜI	Übersicht verwendeter Hilfsmittel			
$\mathbf{Li}$	List of Figures			
$\mathbf{Li}$	List of Tables			
Bi	Bibliography			
A	Appendix A: Interview Material      A.1: Official Interview Invitation and Participant Recruitment      A.2: Interview Participant Consent Form      A.3: Interview Guide			
Appendix B: Workshop Material      B.1: Official Workshop Invitation with Agenda      B.2: Workshop Participant Consent Form      B.3: Workshop Location, Setup, and Design - Fostering Cohesion and Network-			<b>147</b> 148 150	
	B.4:	ing Among Participants	$\begin{array}{c} 151 \\ 152 \end{array}$	

# CHAPTER

# Introduction

Given the rising prevalence of dementia and the resulting increase in the number of individuals requiring support[Bun20], current research underscores the urgent need to integrate Assistive Technologies (AT) into dementia care[PEHR21]. While existing Assistive Technologies predominantly address the needs of individuals directly affected by dementia, there is a critical gap in meeting the needs of caregivers, particularly family caregivers.[PEHR21][SMS13]

Family caregivers, the primary focus of this study, play a critical role in both providing support to individuals affected by dementia and mitigating the burden on state resources, which are increasingly strained due to a shortage of certified professional caregivers.[Bun20][PEHR21] Despite their vital contributions, this group faces substantial obstacles in accessing formal care services, including rigorous eligibility criteria and financial limitations.[Bun24b] Consequently, family caregivers must balance caregiving responsibilities with their personal and professional obligations, resulting in notable deficits across multiple areas.[SMS13] These deficits span physical, mental, legal and financial aspects, further exacerbated by the lack of adequate technological solutions to support them effectively.[Ges21][PEHR21][SMS13][Bun20]

To address this gap, the present study aims to examine the current state of family caregivers of people with dementia in Austria, evaluate existing support structures, and explore the potential integration of technology in the given domain. This investigation will involve a comprehensive review of current research, relevant literature, and interviews with experts and individuals with lived experiences. Based on these findings, a Design Thinking Workshop will be conducted to develop targeted recommendations for future improvements, including the creation of functional requirements for future Assistive Technologies specifically tailored to the needs of family caregivers.

## 1.1 Motivation and Problem Statement

According to the Austrian Dementia Report, an estimated 115,000 to 130,000 people suffer from various forms of dementia in Austria. Given the aging population, this number is expected to double by 2050.[Bun20] Although there have been remarkable advances in Assistive Technologies, solutions are mainly tailored to patients, unintentionally overshad-owing the central role of caregivers.[BD09][GVKKS<sup>+</sup>23][NCPSZ23] This underscores a call to immediate action for the state of Austria and relevant organizations to address the needs of distinct associated stakeholders.

While exploring the complex field of caregiving, a crucial differentiation emerges between two distinct groups in the given context. The first comprises certified caregivers, whose primary occupation is caregiving, while the second group includes family members, who manage caregiving responsibilities alongside their own (work) obligations. This dichotomy not only stresses differences in caregiving efficiency and processes but also emphasizes the critical importance of carefully analyzing distinct requirements. As a result, the diverse approaches and levels of involvement reveal the intricate dynamics within the caregiving spectrum, necessitating precisely tailored strategies, structures, and the integration of innovative, individualized Assistive Technologies.  $[FDO^+23][NCPSZ23][Ana23]$ 

Family caregivers play a pivotal role in both providing direct support to individuals with dementia and alleviating the pressure on state resources amid a shortage of professional caregivers. Despite their vital contributions, they encounter significant challenges that undermine their effectiveness and personal well-being.[Bun20][PEHR21]

One major issue is the gradual onset of dementia and the often delayed diagnosis of the condition. Family caregivers frequently begin providing care long before a formal diagnosis is made, resulting in an unprepared and abrupt transition into caregiving roles. This lack of readiness, combined with insufficient training and support, leads to increased stress and reduced caregiving quality. Furthermore, the absence of formal recognition, often stemming from the lack of an official diagnosis, may compel caregivers to perceive their responsibilities as an unquestioned duty.[Hol22][Alz23][Bra09]

Financial constraints further complicate the situation. The unexpected costs associated with caregiving – such as medical supplies and home modifications – can be overwhelming. Additionally, many caregivers face income loss due to reduced working hours or the need to leave their jobs.[FDO<sup>+</sup>23][Ges21]

A further motivating factor for investigating the matter from a technical, solution-oriented perspective is the lack of a centralized information source. Although numerous support services and systems exist in Austria[Bun20][PEHR21][Ges21][Bun23b][Ana23][Int24c] [Wie24] [Car24d], they are fragmented and challenging to navigate, as revealed by a simple internet search. The absence of a comprehensive, centralized support network forces caregivers to contend with a disjointed array of services, may increasing their time and effort while reducing the overall effectiveness of the available assistance.

The emotional and physical burden experienced by family caregivers similarly constitutes a significant obstacle. Balancing caregiving with personal and professional responsibilities often leads to exhaustion and mental health issues. Many caregivers experience high levels of stress, anxiety, and depression, which can adversely affect their health and caregiving capabilities.[Ges21][Wie24][Int24a]

In conclusion, technology might hold substantial potential to address the complex challenges faced by family caregivers. Exploring and developing concepts for Assistive Technologies could open new research directions for product development, offering solutions that enhance caregiving capabilities and overall well-being. This approach could not only support caregivers more effectively but also strengthen the dementia care system, leading to a more balanced and efficient caregiving environment in Austria.

## 1.2 Aim of the Work

The anticipated outcomes of the proposed master's thesis are poised to yield comprehensive insights into the challenges faced by family caregivers in Austria, with a particular focus on the development of targeted solutions to address the identified gaps in current support systems. The culmination of research methodologies, including literature review, expert interviews, and a Design Thinking Workshop, is expected to result in a nuanced understanding of the state of family caregivers and provide actionable recommendations for future improvements.

Hence, the expected results include:

## Identification of Caregiver-Specific Challenges:

The research endeavors to identify and articulate the unique challenges faced by family caregivers in Austria, considering the multifaceted nature of caregiving responsibilities, encompassing physical, mental, and financial aspects, among others.

## Insights into Existing Support Deficiencies:

Through extensive literature review and expert interviews, the study aims to uncover deficiencies in the current support structures available for family caregivers, shedding light on areas requiring immediate attention and enhancement.

## Understanding the Impact of Professional Care Limitations:

By exploring cases where professional care is not a viable option, the thesis seeks to elucidate the impact of limitations in accessing state-financed professional care services, thereby emphasizing the necessity for alternative support mechanisms.

## In-depth Exploration of Family Caregivers' Coping Strategies:

The research aims to delve into the coping strategies employed by family caregivers in the absence of comprehensive professional support, offering insights into their resilience and adaptability.

#### Validation of Design Thinking as an Effective Ideation Practice:

The Design Thinking Workshop is expected to serve as an effective platform for ideation, yielding diverse and innovative suggestions for potential Assistive Technologies tailored to the specific needs of family caregivers. Thereby, active participation by various stake-holders is expected.

#### **Concrete Improvement Suggestions and Concepts:**

Building on the outcomes of the Design Thinking Workshop, the expected results include the formulation of concrete improvement suggestions, concepts, or prototypes for Assistive Technologies that directly address the identified challenges.

In case the thesis identifies an insufficiently grounded basis for a final prototype, the outcome will encompass a conceptual proposal for future actions or solution approaches. This will be supported by references obtained from interviews and the Design Thinking Workshop. Moreover, the findings will also be consolidated into a meticulously documented format, supplemented by refined functional requirements. These artifacts may serve as a foundation for subsequent scientific projects aimed at addressing the challenges encountered by family caregivers through technological solutions or approaches.

#### **User-centered Solutions Reflecting Stakeholder Input:**

The development of user-centered use cases aims to create detailed scenarios that illustrate the practical application and benefits of proposed Assistive Technology concepts in real caregiving contexts. Incorporating feedback from stakeholders gathered during the Design Thinking Workshop will ensure that these solutions are both relevant and practical. Consequently, detailed functional requirements for potential Assistive Technologies and their intended application areas will be developed, providing a clear and actionable outline of the proposed solutions.

To ensure the concepts' effectiveness and practical utility, future research should focus on validating them with stakeholders. This validation process should involve iterative testing and refinement based on stakeholder feedback to confirm that the functional requirements meet the real-world needs of family caregivers. However, due to the current study's focus and the complex nature of the research field, the validation process is beyond the scope of this work.

#### **Proposal for Future Enhancements:**

The culmination of this research is anticipated to lay a solid groundwork for future advancements in support systems and Assistive Technologies for family caregivers, significantly contributing to the ongoing discourse on dementia caregiving in Austria. By focusing on the detailed exploration of the needs and challenges faced by family caregivers, this study aims to provide a foundational framework for understanding the specific areas where technological integration could offer substantial benefits. Furthermore, the research acknowledges and explicitly addresses the hypothetical scenario in which technology may be deemed undesirable. Participants in the study will be appropriately informed of this consideration. In summary, while the current research identifies critical challenges and proposes initial, user-centered solutions, its primary contribution is to set the stage for a more in-depth requirements engineering process.

#### 1.2.1 Research Questions

To comprehensively explore the subject, the proposed research is guided by the following overarching and subsidiary research questions (RQ).

#### **RQ1:** Existing Approaches and Support Systems for Family Caregivers

What are the existing approaches and technological solutions in Austria aimed at supporting family caregivers of people with dementia (PwD), and how can these frameworks be systematically assessed for accessibility, comprehensiveness, and the identification of potential gaps?

**RQ2:** Innovating Technologies & Supportive Structures through Design Thinking Leveraging insights from the Design Thinking Workshop; outcomes of expert interviews; and findings from prior research projects, how can these combined sources be effectively utilized to propose concrete improvements and concepts of potential Assistive Technologies, contributing to enhanced support structures for family caregivers of PwD in Austria?

By addressing these multifaceted questions, this research aims to offer a nuanced and holistic understanding of the complex landscape surrounding dementia caregiving. In doing so, it seeks to contribute valuable insights to the discourse on support systems and technological interventions for family caregivers.

## **1.3** Structure of the Work

The upcoming section highlights the structure of the present master's thesis by systematically navigating the complex terrain of caregiving. It unfolds a structured methodology, including an extensive literature review, expert interviews, and a Design Thinking Workshop, culminating in the utilization of use cases to identify support strategies and concepts of future Assistive Technologies for family caregivers. Each step contributes to a comprehensive exploration of the challenges faced by the target group.

Thereby, the overarching goal is to uncover gaps and develop innovative pathways toward potential solutions and supporting frameworks for family caregivers, with a particular emphasis on assessing the technical feasibility and integration potential of technological interventions.

Hence, the work will be structured as follows:

- Introduction
  - Motivation & Problem Statement
    - \* Establishing the driving force behind the research and articulating the core problems addressed in the study.
  - Aim of the Work & Research Questions
    - \* Clearly defining the main aim of the research and formulating the key questions that will guide the investigation.
  - Structure of the Work
    - \* Providing an overview of how the research is structured, including the main sections and their respective roles.
  - Methodological Approach
    - \* Establishing Methodological & Research Framework
      - Research Design: Developing a structured approach that includes methods for data collection and analysis. This framework guides the research process and ensures alignment with the study's goals.
      - Double Diamond Model: Utilizing the Double Diamond model as a guiding framework to structure the research.
- State of the Art
  - Literature Review
    - \* Examining existing research and developments to position the study within the broader context of current knowledge.
  - Definition of Terms
    - \* Collecting relevant concepts and clarifying key terms to ensure a shared understanding, including potential classifications within caregiving that delineate various caregiver roles and responsibilities.
- The Voice of Family Caregivers & Experts
  - Participant Selection for the interviews
    - \* Defined Criteria: Clear criteria are established for selecting the right candidates.
    - \* Recruitment Process: Detailed recruitment process for identifying and inviting professionals and stakeholders.
  - Interview Protocol
    - \* Structured Content: A comprehensive interview protocol is developed with structured questions.
    - \* Ethical Considerations: Ethical considerations are addressed, ensuring participant confidentiality and informed consent.

6

- Data Analysis
  - \* Coding and Categorization: Coding techniques are employed for categorizing and analyzing interview data.
  - \* Thematic Analysis: Key themes and patterns emerging from interviews are identified.
- Engaging Family Caregivers and Experts Outlining the Design Thinking Workshop
  - Design Thinking Workshop Structure
    - \* The Design Thinking Workshop structure is outlined, incorporating collaborative elements.
  - Facilitation Approach
    - \* The facilitation approach is described to ensure active participation.
  - Data Capture
    - \* Methods for capturing insights and ideas generated during the workshop are employed.
  - Evaluation
    - \* Evaluating the collected data and Design Thinking Workshop outcomes, with a specific focus on assessing the effectiveness of the workshop.
- Utilizing Use Cases to Identify Support Strategies & Concepts of Future Assistive Technologies for Family Caregivers
  - Use Case Development
    - \* As an integral component of the use cases, scenarios will be outlined and tailored to specific user needs. This phase aims to effectively translate conceptual ideas into technical requirements, resulting in clear functional descriptions of the envisioned solutions.
    - \* The complexity of the current study necessitated a focused approach that excludes the validation of stakeholder perspectives at this stage, thereby emphasizing the necessity for future research.
  - Interpretation of the Results
    - \* Each use case within a selected problem space will be analyzed to capture the unique contexts in which family caregivers operate, focusing on their specific requirements and the functionalities needed in potential Assistive Technologies.

- Discussion & Conclusion
  - Critical Reflection: Interpretation of Findings and their Significance
    - \* An in-depth analysis of the research findings, interpreting their significance within the broader context of the study's objectives. This section will explore connections between the results and the research questions, providing a comprehensive understanding of the outcomes.
  - Limitations
    - \* A critical examination of the study's limitations, acknowledging and addressing potential constraints that may have influenced the research process or findings. This reflective analysis aims to enhance the transparency and validity of the study and provides insights on how the conducted study could be improved.
  - Implications and Recommendations
    - \* An exploration of the broader implications of the study's findings for family caregivers. This section will also provide actionable recommendations for future research endeavors or practical interventions centered around family caregivers, contemplating potential subjects for subsequent theses based on the current research insights.

## 1.4 Methodological Approach

The present chapter outlines the research methodology employed to support the study's findings. It specifies the techniques utilized and their relevance to the research objectives. Additionally, it establishes essential parameters and boundaries to ensure the study is tailored effectively to the needs of family caregivers. This methodological framework is crafted to ensure a clear and focused approach, with each technique systematically contributing to the study's overarching objectives.

Therefore, the selected methodologies will be applied sequentially, each informed by insights derived from preceding phases of the study.

#### 1. Literature Review

a) Accumulating background information to establish the theoretical foundation of the proposed thesis.

## 2. Interviews - Comprehensive Exploration of the Caregiving Landscape

- a) Utilizing semi-structured expert interviews to gather comprehensive insights and assess the current landscape of support structures for family caregivers. This involves engaging candidates from relevant organizations, governmental bodies, and key stakeholders to ensure a broad and informed perspective.
- b) The second group of interview candidates focuses on caregivers, particularly those with lived experiences. This includes both, professional and informal, hence family caregivers. The aim is to gain deeper insights into current challenges, requirements, and provide a foundation for potential future solutions.
- c) Excluding individuals with dementia as well as young carers from the thesis scope is a deliberate choice grounded in the specialized training, essential for conducting interviews with this group that is beyond the scope and focus of the present work.

## 3. Interview Analysis

- a) Following the compilation of data from the structured interviews, a deeper analysis will be conducted. This process aims to draw conclusions that unveil current shortcomings and gauge potential areas for improvement or exploration.
- b) Additionally, the interviews will delve into participants' opinions on the planned Design Thinking Workshop. This will include their openness to collaborative idea generation, initial impressions, and thoughts on the overall usefulness of this innovative approach.

## 4. Design Thinking Workshop

- a) Employing a methodological approach, the Design Thinking Workshop will delve into the needs of family caregivers and explore potential technological solutions, with a specific focus on Assistive Technologies. The design process will be collaboratively guided by stakeholders, emphasizing co-creation. Insights from various roles within the caregiving landscape and relevant stakeholders during the ideation phase will ensure a comprehensive perspective on future product or service requirements. This approach aims to enrich understanding of the anticipated needs and expectations for forthcoming Assistive Technologies tailored to family caregivers.
- b) The composition of the workshop, especially concerning the participants will remain flexible, determined in light of the outcomes from expert interviews. This dynamic approach is driven by several considerations, including the establishment of minimal predefined requirements and the aspiration for a mixed participant profile. Ideally, this mix would encompass leaders of organizations, family caregivers, and professional caregivers. By adopting this strategy, the workshop aims to foster a multidisciplinary environment, facilitating diverse perspectives and enriching the collaborative ideation process.

#### 5. Individualized Use Cases

- a) Building upon insights gathered from interviews and the Design Thinking Workshop, the creation of use cases becomes a tangible outcome. These use cases serve as essential tools, laying the foundation for future improvements and the design of Assistive Technologies tailored to the specific needs of family caregivers. Thereby, this approach ensures that technological solutions are grounded in real-world needs, fostering user-centered innovation and facilitating ongoing enhancements in caregiving support systems.
- b) As a central component of the use cases, scenarios will be outlined to address user needs. This phase aims to effectively translate conceptual ideas into technical requirements.
- c) As highlighted, the present study will not validate these prototypes with stakeholders due to the complexity of the study, which necessitates a more focused approach and indicates a need for future work in this area.

#### 6. Discussion - Systematic Analysis and Interpretation of the Outcome

- a) The outcomes of the applied research methods will undergo thorough analysis and interpretation, scrutinizing societal, economic, ethical, and technological dimensions to extract comprehensive insights.
- b) Reflecting on the interviews, the discussion will explore gaps in current support structures in Austria and evaluate potential meaningful approaches for aiding family caregivers. Additionally, it will delve into the role of Design Thinking in fostering ideation, and how use cases can translate into tangible improvements, guiding future work, changes, and developments.
- c) A critical examination of the limitations inherent in the study's methodology and scope will be addressed to provide transparency and contextualize the findings.

#### 1.4.1 Utilizing the Double Diamond Model as a Research Framework

Beyond the presented focus and methodological framework, a guiding research framework, the *Double Diamond Model (2004)* will be utilized. This model helps in systematically exploring and defining the problem space, developing and testing potential solutions, and refining the research outcomes, as presented in the figure below.[Des24b]

The *Double Diamond Model*, developed by the Design Council in 2004, is grounded in the contributions of several pioneers, including Herbert Simon, Thomas Marcus, Thomas W. Maver, Bela H. Banathy, Barry Boehm, Paul Souza, and Nigel Cross, who made significant strides in design theory and methodology during the latter half of the 20th century. Their work has profoundly influenced fields such as design science, systems thinking, and engineering design processes.[Ban96][Des24a]



Figure 1.1: The Double Diamond Model

Source: Created by Author based on Double Diamond Model by Design Council[Des24b]

The primary objective of the design model is to promote a structured approach that enables the development of specific user-centered solutions through the systematic exploration of associated problems and potential solutions.[Des24a]

Thereby, the model is divided into **four distinct phases:** discover, define, develop, and deliver. Each is visually represented by two interconnected diamonds, illustrating the processes of divergent and convergent thinking.[Des24b]

Divergent thinking is a cognitive process used to generate creative ideas by exploring many possible solutions. It emphasizes quantity over quality initially, encouraging spontaneous, free-flowing thinking where multiple ideas and possibilities are considered. In contrast, convergent thinking is used to narrow down these ideas into a more specific, potentially single best solution. This process involves evaluating and selecting the most viable option from the possibilities generated during divergent thinking, shifting the focus to quality over quantity.[Des24b]

Now, linking back to the distinct phases, in the **discover phase**, an extensive exploration is undertaken to gather insights and understand all relevant problems, their underlying causes, and potential effects. This phase emphasizes divergent thinking to broaden the scope of understanding.[Des24b] In the present study, this phase corresponds to the literature review as outlined in chapter, *State of the Art*.

During the **define phase**, the information and insights gathered in the Discover phase are synthesized to pinpoint and articulate the core issues. This phase marks a transition from divergent to convergent thinking, with the aim of clearly defining the problem statement and identifying the core issue to be addressed.[Des24b] In this study, the define phase is associated with the interviews and subsequent analysis.

The **develop phase** focuses on ideation and prototyping, where a wide range of potential solutions are brainstormed, experimented with, and iteratively tested. This phase returns to divergent thinking, encouraging creative exploration and iterative refinement of ideas.[Des24b] During the develop phase, a Design Thinking Workshop will be conducted, where relevant ideas will be developed in collaboration with the target group and selected stakeholders.

Last, the **deliver phase** involves the selection, final refinement, and implementation of the best solutions. This phase includes thorough testing, final adjustments, and the launch of the solutions, ensuring they are effective and viable for deployment.[Des24b] Based on the previously gathered data and insights, the deliver phase in this study will involve defining individualized use cases. Given the complex nature of the present research, this phase will not present a complete design solution. Thus, within the Double Diamond Model, the final phase serves more as a preliminary solution concept rather than a finished product or prototype, intended to lay the groundwork for future product ideas and feature requirements. Moreover, the scope of this study does not extend to testing the proposed solutions, as this would exceed the intended boundaries of the current investigation. Instead, the focus is on establishing these foundational concepts, which may pose opportunities for further exploration and testing in future work.

In conclusion, the Double Diamond Model serves as a guiding tool for systematically progressing from a problem statement to a potential user-centered design concept, particularly for family caregivers.

#### 1.4.2 Responsible Research Practicies and Ethical Mentorship

Due to the sensitive nature of the given domain, a rigorous ethical framework has been integral to the entire study process, encompassing goal setting, methodology, and implementation. From the outset, ethical mentorship provided by TU Wien has been incorporated to ensure that all aspects of the research are aligned with the principles of responsible research practices. Thereby, Dr. Astrid Weiss, a member of the TU Wien ethical mentorship team, has overseen and supervised the study, ensuring adherence to the highest ethical standards throughout.[TU 24a]

This collaboration reflects TU Wien's commitment to supporting researchers in addressing ethical requirements and maintaining research integrity. The university's dedicated unit for Responsible Research Practices advises on ethical issues and promotes the conditions necessary for responsible research in contemporary settings.[TU 24b] This guidance has been pivotal in shaping the study's objectives, validating research methodologies, ensuring the accuracy and ethical rigor of research materials, and overseeing the anonymization and management of data among others.

Ethical considerations, particularly those related to research participants, such as participant consent, confidentiality, and data handling, have been meticulously addressed in accordance with relevant legal regulations and standards. This approach ensures the protection of participants' rights and enhances the credibility of the research findings. Aligned with the core principles of research integrity – reliability, honesty, respect, and accountability – participants will be transparently informed about data handling and the subsequent steps in the research process, ensuring full compliance with ethical standards at every stage of the study.[TU 24b]

In summary, the selected methodologies encompass comprehensive insights derived from expert interviews, Design Thinking Workshops, and user-centric use cases among others. This holistic approach, complemented by a thorough analysis and interpretation, aims to forge innovative solutions for supporting family caregivers of individuals with dementia in Austria. The methodological journey, marked by inclusivity and iterative refinement, lays the groundwork for a nuanced understanding and actionable enhancements in this critical domain.

With each research method employed, a new phase of the Double Diamond Model will be entered, which will be explicitly highlighted and further discussed in the respective chapter.



# CHAPTER 2

# State of the Art

The current chapter presents a thorough examination of the landscape of family caregivers of people with dementia in Austria. First, it establishes a theoretical foundation by defining key concepts and terminologies relevant to the field. Subsequently, the chapter offers a detailed analysis of the complex challenges encountered by family caregivers and the existing support structures. Thereby, special attention is paid to the role of Assistive Technologies in caregiving practices, evaluating both current implementations and the potential benefits of further technological integration.

This comprehensive analysis aims to provide an in-depth understanding of the current caregiving environment and to identify strategic opportunities for enhancing support through the adoption of technological innovations and overall involvement.

Another critical aspect involves defining the direction for the upcoming semi-structured interviews, which will be detailed in *Chapter 3*. This includes establishing the focus of the research method and crafting the specific questions for the interview guide.

As presented in the first chapter within subsection *Methodological Approach*, the current chapter enters the first phase of the *Double Diamond Model*, the discover phase, illustrated in the subsequent figure. In this phase, the emphasis lies on obtaining a comprehensive understanding of the current situation of family caregivers in Austria, moving beyond assumptions and socially constructed stereotypes to accurately defining the problem space.



Figure 2.1: Double Diamond Model - Phase 1: Discover Source: Created by Author based on Double Diamond Model by Design Council[Des24b]

To achieve this, the research employs divergent thinking, which involves investigating a wide range of issues within the caregiving landscape through comprehensive exploration and critical analysis of the state of the art.

#### $\mathbf{2.1}$ Family Caregivers of People with Dementia in Austria

Assuming the role of a family – non-professional, non-certified or informal – caregiver, while managing personal and professional obligations involves significant responsibility and liability that must be recognized, respected, and appropriately compensated. [PBL<sup>+</sup>20] This role not only eases the burden on the immediate family but also has broader implications at the state level. Particularly due to resource limitations, such as the shortage of professional caregivers and financial constraints, among others. [FDO+23][Bun23a]

The significance of the role and the need for support for family caregivers is emphasized by various stakeholders, including the Austrian government – specifically, Federal Ministry of Social Affairs, Health, Care and Consumer Protection [Bundesministerium für Soziales, Gesundheit, Pflege und Konsumentenschutz (BMSGPK), short Sozialministerium] – as reflected in the following statement[Bun23a]:

"Betreuende Angehörige sind nicht nur der "größte Pflegedienst" Österreichs, sondern auch eine der tragenden Säulen unseres Pflegevorsorgesystems. Aus diesem Grund ist es notwendig, die Situation pflegebedürftiger Menschen und ihrer Angehörigen stets zu verbessern."[Bun23a]

The above-cited statement appears in the document, "Angebote für Angehörige von Menschen mit demenziellen Beeinträchtigungen - Ein Produkt der Demenzstrategie", issued by the BMSGPK. Serving as a supplementary product of the Dementia Strategy [Demenzstrategie][Sab15], it provides an in-depth analysis of the roles and challenges encountered by family caregivers, along with a detailed review of available support mechanisms.[Bun23a] These aspects will be further explored in the upcoming sections.

## 2.1.1 Trends and Facts

Moving toward the examination of numerical data, a significant gap in detailed statistical research and precise estimates, regarding the total number of family caregivers for individuals with dementia in Austria is apparent.

Broader estimates provided by BMSGPK suggest that approximately 947,000 individuals in Austria are engaged in caregiving for relatives or affiliates with various health conditions. Among these caregivers, an estimated 42,000 are classified as *young carers* – a subgroup consisting of individuals under the age of 18 – who face additional challenges related to their caregiving responsibilities, such as enhanced legal constraints and psychological stress. This further underscores the critical nature and complexity of caregiving.[Int24b][Bun21] For the present study, young carers are excluded from deeper analysis due to the specialized approach required for this sensitive target group, which falls beyond the scope of this research.

Another crucial aspect can be found in the setting in which caregiving takes place. Recent data indicates that – excluding the number of young carers – 801,000 family caregivers provide care in home environments, whereas the remaining 146,000 family caregivers are involved in providing care and support within inpatient long-term care [stationäre Langzeitpflege] settings.[Bun24a]

Given this fact, over 80% of caregiving activities occur in private home settings, necessitating age-appropriate modifications to home environments and additional measures to ensure accessibility and barrier-free living.[Int24b]

Additionally, a substantial proportion of informal caregivers do not receive professional assistance; only a portion accesses supportive services such as professional home care or mobile care.[Int24b][Bun21]

Such a high proportion of home-based caregiving not only highlights the substantial personal commitments performed by caregivers but also underscores their vital role in the social support system, along with their considerable economic impact.

Further demographic patterns indicate that caregiving responsibilities are predominantly undertaken by women. Specifically, in home-based care, women account for approximately 73% of caregivers, reflecting an imbalanced gender distribution in caregiving roles.[Bun21]

## 2.1.2 Classification of Informal Caregivers

The numerical data presented above offers insights into broader trends and patterns within the non-certified caregiving landscape in Austria.

It encompasses caregivers who support individuals with various health conditions, not solely those affected by dementia. Hence, the data is not restricted to a single diagnosis.

Moreover, a detailed examination of the presented data, combined with a thorough review of available sources and commonly used media terminology, reveals the need to incorporate additional metrics in the context of non-certified caregivers. This includes understanding specific legal classifications and introducing relevant terms essential to the current research.

According to Austrian legislation, when evaluating available support services, it is essential to differentiate between two primary categories of informal caregivers: family caregivers (FC) [pflegende Angehörige] and caregiving affiliates or associates [pflegende Zugehörige]. Although the German terms might appear interchangeable or easily confused, they refer to distinct groups with specific legal rights, social benefits, and eligible services. Clarifying these distinctions and understanding their legal statuses are considered crucial to developing a robust research framework and to facilitating a more precise analysis of caregiving dynamics.[Wie24]

Thus, the term family caregivers refers to individuals who take on caregiving responsibilities for their family members or relatives. This category includes among others, parents, children, siblings, spouses, registered partners, and sometimes extended family members such as aunts, uncles, or cousins. The focus here is on the familial relationship and the legal rights and benefits that accompany it. Family caregivers are often eligible for various forms of support, including care allowance [Pflegegeld], care leave [Pflegekarenz], and pensions or social security benefits related to their caregiving activities, which will be examined in more detail in the upcoming section.[Bun24a][Bun21][Pen24]

In contrast, caregiving affiliates or caregiving associates are those who provide care but are not necessarily family members. This group includes close friends, neighbors, or community members who are involved in caregiving. These caregivers have a significant relationship with the care recipient but are not related by blood, marriage, or other legally regulated close familial relationships. The benefits and support available to caregiving affiliates can vary and are often less comprehensive than those available to family caregivers. However, in some contexts, they may still be eligible for certain types of support, especially if they have a formal caregiving arrangement.[Bun24a][PEHR21][Bun21][Pen24][Öst23] Understanding these distinctions is crucial for navigating the legal and social support systems for caregivers in Austria.

#### Excursus: Considerations and Scope of the Study (1)

To ensure a sharper focus, when the term "caregivers" appears in the upcoming sections, it will predominantly refer to informal family caregivers, unless otherwise specified, and will exclude professional, hence formal caregivers, as well as caregiving affiliates or caregiving associates.

Now, by acknowledging the aforementioned observations and research focus, a thought experiment emerges as justified, narrowing the scope from a generalized target group to specifically address family caregivers of PwD.

Approaching the estimation of the number of family caregivers for individuals with dementia in Austria from a different angle might involve correlating it with the prevalence of dementia in the country. Recent data indicates that approximately 115,000 to 130,000 Austrians are affected by dementia. Given ongoing demographic trends and increasing life expectancy in the coming years, this number is expected to rise significantly.[Bun20] However, a direct mapping of the number of PwD to the number of family caregivers may not be feasible due to several factors. First, caregiving responsibilities might be shared among multiple individuals or alternate between different stakeholders. Consequently, the available data might not fully capture the complexity of caregiving dynamics. Second, diagnosing dementia remains challenging, as there is no definitive method to detect the early stages of the impairment. Hence, the process from initial symptoms to a final diagnosis may span several years.[Hol22][Alz23][Bra09]

## 2.2 Current Support Structures in Austria

Navigating the intricate landscape of family caregiving challenges, the **Federal Ministry** of Social Affairs, Health, Care and Consumer Protection (BMSGPK) plays a pivotal role in Austria by providing essential guidance and information. The focal point resides in the key support structures accessible through their website under the subpage "*Betreuende und pflegende Angehörige*", a testament to the dynamic nature of caregiving influenced by health, life circumstances, and financial considerations, along with tangible sources of assistance. To offer a glimpse into the nature of the services tailored for family caregivers, the key points from this website are briefly listed as follows:[Bun23b]

• Family Discussion [Angehörigengespräch]

Psychologist-led discussions, available in-person, by phone, or online, offering up to ten sessions to support family caregivers emotionally.[Bun23b]

- Information and Consultation through Home Visits [Hausbesuche] Home visits by qualified healthcare professionals commissioned by the Social Ministry, providing assessments, information, and advice on caregiving situations.[Bun23b]
- Family Caregiver Bonus [Angehörigenbonus]
  Financial bonus for those caring for close relatives receiving at least Pflegegeld Stufe
  4. Other close relatives can apply for the bonus if they meet specific criteria.[Bun23b]
- Care Leave Allowance [Pflegekarenzgeld] Enables caregivers to take leave from work for caregiving. The amount depends on income and other factors, providing financial support during caregiving periods.[Bun23b]

- Subsidies for Replacement Care Costs [Zuwendungen zu den Kosten der Ersatzpflege] Grants for temporary replacement care when primary caregivers are temporarily unable to provide care.[Bun23b]
- Courses on Caregiving [Pflegekurse] Support for family caregivers attending caregiving courses, with an annual maximum allowance of €200.[Bun23b]
- Young Carers and Youths [Pflegende Kinder und Jugendliche] Studies address the challenges faced by young caregivers, who provide significant care to family members. A dedicated app, "YoungCarers Austria" provides information and support.[Bun23b]
- Pension Insurance for Caregivers [Pensionsversicherung für pflegende Angehörige] Thereby, two options exist: Continued Insurance [Weiterversicherung] and Selfinsurance [Selbstversicherung] for caregivers, allowing them to accrue pension insurance without paying contributions.[Bun23b]
- Health Insurance for Caregivers [Krankenversicherung für pflegende Angehörige] Co-insurance [Mitversicherung] and Self-insurance [Selbstversicherung] options are available for caregivers, ensuring health coverage during caregiving.[Bun23b]

## 2.2.1 Further Support Services and Organizations for Family Caregivers in Austria

It is essential to recognize the significant contributions of various institutions and organizations in Austria that provide additional support to family caregivers. Thereby, support extends beyond those caring for individuals with dementia, addressing the diverse needs of caregivers in a variety of situations. For the purposes of this thesis, four prominent entities – Caritas Pflege, Fonds Soziales Wien (FSW), Gesundheit Österreich GmbH (GÖG), and the Interessengemeinschaft pflegender Angehöriger – have been selected for further investigation based on their services and presence within the caregiving community. These entities play crucial roles and collaborate, in some form, either with each other and/or with the Federal Ministry of Social Affairs, Health, Care, and Consumer Protection (BMSGPK) to inform policy, support initiatives, and enhance the caregiving infrastructure.[Car24c][Fon24a][Ges24b][Int24c]

Hence, the subsequent summary enumerates a selection of services offered by these institutions to emphasize the types of support accessible to family caregivers.

**Caritas Pflege** is one of Austria's largest providers of care and support services, dedicated to enhancing the quality of life for individuals in need of care. The organization focuses on supporting individuals who require assistance to maintain their independence and offers professional guidance to family caregivers navigating the complexities of caregiving.[Car24c][Car24e]

In addition to its core services, Caritas has developed the *Café Zeitreise*, a specialized program aimed at fostering connections among families of individuals living with dementia.
This initiative is regularly hosted in various districts of Vienna and extends to other regions across Austria. It provides a supportive environment, where individuals with dementia and their family caregivers can engage, share experiences, and exchange valuable information.[Car24b]

To highlight some of their services, Caritas Pflege offers a variety of programs designed to support family caregivers, including:

- *Regional Services*: Quick access and an overview of available services by region, including options for caregiving assistance and regional networking opportunities. [Car24a]
- *Courses and Workshops*: Caritas organizes seminars and lectures for family caregivers, with offerings varying by region in Austria.[Car24a]
- *Relief Services*: Recognizing the challenges of daily caregiving, Caritas provides various programs to alleviate the burden on caregivers, including in-home care services and discussion groups.[Car24a]
- *Consultation Services*: Offers guidance and information to caregivers about the different forms of support available, ensuring they are prepared for both acute situations and long-term care needs.[Car24a]
- Community and Networking Opportunities: Facilitates connections among family caregivers and hosts events to share experiences and support each other, such as the Café Zeitreise.[Car24b]

Fonds Soziales Wien (FSW) ensures that residents of Vienna, particularly those facing challenging life situations, have access to essential social services, including care, regardless of their financial circumstances.[Fon24a]

A key initiative by one of FSW's subsidiaries is the *Netzwerk für pflegende An- und Zugehörige*, a pilot project designed to provide comprehensive support to family caregivers. This network aims to enhance the societal recognition of caregiving roles and alleviate the burdens associated with caregiving.[Wie24]

Hence, the portfolio of FSW includes the following services, among others:

- In-Home Care and Support: Professional assistance with daily living activities, medical care, and home maintenance to enable individuals to remain in their homes.[Fon24b]
- *Day Care Centers*: Professional care, activation, and engagement activities outside the home.[Fon24b]
- *Residential Care*: Various housing options for individuals who require enhanced care, including temporary and permanent stays in care facilities.[Fon24b]

- *Relief and Empowerment*: Practical knowledge shared among caregivers, regular meetups for exchange and networking, access to a comprehensive knowledge platform, besides free counseling sessions with psychologists.[Wie24]
- Educational Offerings: The College for Family Caregivers offers free, practical modules that cover numerous topics such as essential caregiving skills, including medical and nursing knowledge, self-care, and stress reduction practices. These programs are designed to provide family caregivers with the necessary skills and knowledge to support their demanding and socially vital roles.[Wie24]

**Gesundheit Österreich GmbH (GÖG)** serves as Austria's central research and planning institute for healthcare and acts as a key agency for health promotion, operating as a non-profit organization under the Austrian government.[Ges24b]

One of its key initiatives is referred to as the Info Platform for Care and Support [Infoplattform für Pflege und Betreuung], launched in December 2021[Inf24], and is accessible at https://www.pflege.gv.at. This platform offers comprehensive and accessible information on care services throughout Austria, directing users to the appropriate resources and institutions, with a particular focus on family caregivers. Notably, GÖG actively engages various target audiences in its projects to address and collect firsthand information on stakeholder needs within the care system.[Ges24b][Ges24a]

Thereby, the website provides following information specifically for family caregivers:

- *General Support:* Resources for home caregivers, covering daily assistance and options for relief and recovery.[Inf24]
- *Care Guidance:* Guidance for caregivers of children with disabilities and support for managing dementia care.[Inf24]
- *Practical Tools:* Checklists for caregiving responsibilities and multilingual training resources offering practical advice to improve caregiving routines.[Inf24]

**Interessengemeinschaft pflegender Angehöriger** advocates for the interests of family caregivers in Austria. The organization was founded in November 2009 after an event organized by the Austrian Rotes Kreuz, aimed at representing the interests of family caregivers and raising public awareness of their roles.[Int24f]

With family caregivers as its primary target group, it provides the following services, among others:

• *Extensive Information on Care Topics*: Provides useful information and links related to various aspects of caregiving, including but not limited to, financial matters, legal matters, government agencies and other public institutions, helpful apps, among others.[Int24c]

- *News and Tips*: Provides updates and news on caregiving topics, and offers practical advice and insights to help caregivers manage their responsibilities more effectively.[Int24d]
- Community and Networking Opportunities: Facilitates connections among caregivers to share experiences and support each other.[Int24e]

It is important to note that, in addition to the institutions highlighted, numerous other organizations also contribute significantly to supporting family caregivers. However, to maintain the focus of the present study, the aforementioned institutions have been chosen as the primary subjects of investigation. This selection is intended to narrow the scope for a more detailed and focused analysis and does not imply any qualitative judgments or evaluations of the services provided by other organizations.

In conclusion, in this array of services, while addressing various aspects of caregiving, the integration of Assistive Technologies remains underexplored, indicating a potential area for further enhancement and tailoring to individual needs.

# 2.3 Assistive Technologies for Family Caregivers in Austria

Following the comprehensive analysis of the study's target group – family caregivers – along with their current situation and the available support frameworks in Austria, it is equally essential to examine the study's additional perspective: the role of Assistive Technologies within the caregiving setting.

#### Excursus: Considerations and Scope of the Study (2)

In this study, the general nature of the term, Assistive Technologies, will be utilized to allow for a comprehensive and unrestricted exploration of relevant technologies. While numerous specific subcategories and related terms of AT, such as digital AT, intelligent AT, Assistive Systems (AS) or Active and Assisted Living (AAL) exist, the study will refrain from limiting the scope to any one of these categories at the outset.[PEHR21][SMS13][Lau24][Wor24][Wor22] This open approach is necessary to ensure that technological observations remain broad, only narrowing once the specific requirements of the study's target group, family caregivers, are clearly identified. Instead, it will first carefully analyse the needs of the target group using a technical lens. Whether technology should be personalized or remain general, will be determined based on the outcomes of interviews and the Design Thinking Workshop. This open approach is crucial given the sensitive nature of the domain, accompanied by ethical considerations that will be later addressed.

At the same time, the study recognizes the challenge of establishing a precise

definition of Assistive Technologies. The broad scope of the term, combined with the slightly varying wording of its available definitions, allows for multiple interpretations, adding an additional layer of complexity.

Moreover, family caregivers are often not consistently acknowledged as a key target group in literature and other relevant sources in the context of ATs.[Wor24][Ame24] The *assistive* aspect of the term may suggest, or implicitly prioritize, individuals with impairments – as PwD – as the primary focus, overlooking the crucial role of other stakeholders, such as caregivers, in the design and development of ATs.[Ame24] This oversight may raise questions about the appropriateness or create ambiguity in applying Assistive Technologies to a target group without disabilities. To clarify this issue, the subsequent sections will further investigate and explain this dilemma. Consequently, the study will define AT from a perspective that emphasizes the inclusion of family caregivers as relevant stakeholders. This approach does not prioritize one group over another but rather sharpens the study's focus.

#### 2.3.1 Understanding Assistive Technologies

In 2022, the WHO, in collaboration with UNICEF, released the Global Report on Assistive Technology, which conveys extensive global data on Assistive Technologies. [Wor22] [Wor24] Accordingly, as stated on their website, the WHO defines the term, Assistive Technologies as: "... an umbrella term for assistive products and their related systems and services." [Wor24]. "Assistive products can range from physical products such as wheelchairs, glasses, prosthetic limbs, white canes, and hearing aids to digital solutions such as speech recognition or time management software and captioning." [Wor24].

Hence, Assistive Technologies include various products designed to manage daily life, enabling individuals to live more independently. These solutions primarily support individuals with disabilities, allowing them to maintain autonomy and reside in their home environments for extended periods. By facilitating independence, these technologies enhance daily living capabilities, enabling users to perform essential tasks more effectively or bridging the gap until they receive assistance from caregivers. Key features of such AT often include support for social interaction, memory enhancement, leisure activities, location tracking, and health monitoring.[PEHR21][Wor22][SMS13]

While the present study focuses on family caregivers, it is important to point out that Assistive Technologies are primarily designed for individuals with disabilities. A review of existing resources reveals that caregivers, particularly family caregivers, may not be explicitly highlighted as a key target group.[Wor24][PEHR21][SMS13][Sab15][Bun23a] The WHO identifies the primary target groups benefiting from AT as "...older people, children and adults with disabilities, people with long term health conditions such as diabetes, stroke and dementia.". This includes individuals with certain forms of impairment or disability on a global level, without addressing caregivers.[Wor24]

In Austria, approximately 80% of individuals requiring care, receive support at home from family caregivers. This significant reliance on family caregivers underscores the necessity of exploring how Assistive Technologies can be optimized to enhance caregiving efficiency and improve overall well-being.[ös24][Int24b][Bun21]

To achieve this, it is essential to recognize family caregivers, alongside other stakeholders, as a core target group in the development of Assistive Technologies. Their needs and perspectives apparently differ from those of the individuals they care for, indicating that effective technology solutions must take into account the nature of their support and the challenges they face.[Ame24][Bun23a][SMS13]

By understanding and addressing the specific needs of family caregivers, a more inclusive and user-centered approach to technology development can be established. This approach not only benefits caregivers in their daily tasks but also enhances the quality of care provided to recipients. Ultimately, such improvements might positively influence the entire caregiving ecosystem, fostering a collaborative environment that promotes better health outcomes for all involved.[Ame24][PEHR21]

By optimizing support and assistance, Assistive Technologies can enable caregivers to perform their roles more effectively and easily, promoting independence, improving quality of life, and ensuring safety for both caregivers and care recipients. [SMS13][Ana23] The importance of addressing the current circumstances of family caregivers for individuals with dementia in Austria is underscored in the Austrian Dementia Strategy. [Sab15] This strategy advocates for the implementation of effective measures aimed at enhancing the living conditions of both individuals with dementia and their caregivers [Sab15], stating that: "Die österreichische Demenzstrategie befördert damit die Umsetzung von wirksamen Maßnahmen, die die Lebenssituation von Menschen mit Demenz und ihren An- und Zugehörigen verbessern sollen (Juraszovich et al. 2015). Der Unterstützungsbedarf im Alltag derer, die mit Demenz leben, steigt, ebenso jener der pflegenden und betreuenden An- und Zugehörigen<sup>1</sup>, welche zu einem hohen Anteil Frauen sind." [PEHR21]. Defined within an allocated project investigating Assistive Technologies at the intersection of dementia care in Austria, as part of the Austrian Dementia Strategy. [PEHR21] Furthermore, it highlights the importance of user-centered design, including usability

principles in Assistive Technologies, to effectively support daily activities: "Assistive Technologien können, wenn sie entsprechend nutzungsorientiert gestaltet sind, in bestimmten Teilbereichen der Alltagsbewältigung hilfreich sein.".[PEHR21]

#### 2.3.2 Overview of Current Assistive Technologies in Austria

This section presents a brief overview of two prominent Assistive Technologies in Austria that support family caregivers. Each technology serves a distinct purpose and employs different technological solutions.

#### Application in Practice (1): Alles Clara

Alles Clara is a digital platform <sup>1</sup>, developed to support family caregivers in Austria by facilitating comprehensive care coordination and providing professional advice. This free app connects caregivers with trained consultants in nursing and psychology, effectively bridging the gap between care needs and expert guidance.[All24]

The app's features enable caregivers to efficiently manage scheduling, communication, and resource allocation, thereby enhancing their organizational capabilities. A notable aspect of Alles Clara is its documentation feature, which allows caregivers to maintain a detailed caregiving history. This documentation not only helps caregivers track the health status and progress of care recipients but also ensures that relevant information is readily available for consultations with professionals. By offering online counseling, caregivers gain access to expert insights that address various care-related challenges, empowering them with knowledge while alleviating the emotional burden often associated with caregiving.[All24]

Additionally, Alles Clara contributes to job enrichment for consultants, who benefit from a flexible work environment that reduces physical demands. This innovative design supports the mental well-being of caregivers while fostering the development of new professional fields within nursing and psychology.[All24]

The impact of Alles Clara extends beyond individual users; it plays a vital role in the broader Austrian healthcare system by providing an accessible and scalable solution for the large population of family caregivers. Users have reported significant improvements in their ability to manage caregiving tasks, resulting in reduced stress and a more balanced approach to their responsibilities. The availability of professional advice through the app has been particularly valued, as it offers caregivers a reliable source of information and support tailored to their unique challenges.[All24][AK 24][Amt24]

Overall, Alles Clara exemplifies the potential of a visually appealing digital platform to enhance the quality of care for families while simultaneously supporting the professionals who assist them, thereby creating a more effective and sustainable caregiving ecosystem. However, research examining its effectiveness through formal studies is currently lacking, suggesting a need for further investigation.

#### Application in Practice (2): AMIGO

A further, yet distinct in nature, approach to Assistive Technology in caregiving is exemplified by **AMIGO**, an innovative solution within assistive robotics specifically designed to support individuals with dementia. The primary goal of AMIGO is to enhance the well-being of these individuals through a combination of social robotics and multimodal interventions.[PSZ<sup>+</sup>19] At the core of the AMIGO system is Pepper[PSZ<sup>+</sup>19], a commercially available and customizable humanoid robot designed to adapt its functionalities to the specific needs of various user groups.[Sof24] Additionally, the Austrian project

<sup>&</sup>lt;sup>1</sup>https://www.alles-clara.at

recognized the critical role of caregivers – both formal and informal – in managing dementia care. By integrating user-friendly interfaces, AMIGO facilitates the planning and execution of daily activities, which empowers caregivers to manage their responsibilities more effectively, allowing individuals with dementia to remain at their home environment for longer periods.[PSZ<sup>+</sup>19]

AMIGO utilizes two main frameworks: the *coach* and the *companion framework*.[PSZ<sup>+</sup>19] The coach framework utilizes social robotics to motivate and engage individuals with dementia in daily cognitive and physical activities. This component is designed to sustain and potentially improve the cognitive functions and physical capabilities of these individuals by incorporating stimulating exercises into their daily routines.[PSZ<sup>+</sup>19] While the companion framework complements the coach by fostering a long-term, supportive relationship between the robot and the user. The robot actively engages the individual by inquiring about their current health status, reminding them of important actions, and participating in conversations. Additionally, it includes an entertainment feature, designed to reduce feelings of isolation.[PSZ<sup>+</sup>19]

Numerous impacts can be identified with the AMIGO system, particularly in the areas of personalized motivation and cognitive stimulation. By utilizing advanced sensors such as motion analysis and eye-tracking technologies, AMIGO can adapt its interactions based on users' responses. This adaptability ensures that training activities are not only tailored to individual needs but also more effective in maintaining cognitive functions.[PSZ<sup>+</sup>19] Additionally, AMIGO promotes prolonged independence and provides vital support to caregivers. A key objective of the system is to empower both formal and informal caregivers to autonomously plan and manage daily activities. Its user-friendly interfaces simplify this process, making it easier for caregivers to incorporate the robot into their routines. Consequently, AMIGO helps alleviate the caregiving burden, enabling individuals with dementia to remain in their homes for extended periods.[PSZ<sup>+</sup>19]

The research and development process behind AMIGO is informed by an interdisciplinary approach that synthesizes insights, in addition to healthcare, from various other domains such as neuropsychology and information and communication technology (ICT). This comprehensive perspective not only ensures that the system is technologically advanced but also grounds it in the practical realities of dementia care. The interdisciplinary nature and proven effectiveness of AMIGO also serve as a foundational aspect for the present study, highlighting the importance of developing solutions that are both innovative and applicable in real-world settings.[PSZ<sup>+</sup>19]

Moreover, initial implementations of the AMIGO prototype have shown promising results. These findings indicate that AMIGO's ability to adjust its interaction style based on real-time emotional feedback marks a significant advancement in personalized caregiving technology. The system's potential to improve both cognitive and social outcomes for individuals with dementia, while also providing meaningful support to caregivers, underscores its relevance in the evolving landscape of AT with intelligent features.[PSZ<sup>+</sup>19]

#### 2.3.3 Research Approach, Potential Innovations, and Future Directions in Assistive Technologies: An Informal Caregiver Perspective

The previous discussion has revealed a substantial gap in ATs, designed specifically for family caregivers, highlighting the untapped potential of various technological solutions to improve informal caregiving. To effectively harness this potential, it is essential to first identify and understand the specific needs and challenges faced by caregivers.[Ame24] Hence, the present section examines the research approach relevant to the development of efficient Assistive Technologies, emphasizing the significance of Design Thinking as a method for creating user-centered solutions. Following this, the focus shifts to promising innovations and emerging technologies that hold the potential to greatly enhance the caregiving experience, highlighting future directions that address the unique demands of informal caregivers.

#### Design Thinking and Its Relevance within Assistive Technologies

Design Thinking principles are crucial for developing Assistive Technologies that prioritize user-centered design, particularly for family caregivers navigating the complexities of their roles. This approach directly addresses the unique challenges they face by aligning technological solutions with their specific needs and experiences.[Lor23][Aue21]

Engaging caregivers and relevant stakeholders in a co-design process ensures that their requirements are accurately captured, leading to practical implementations that reflect real-world scenarios. By facilitating an environment where participants can express their desires and concerns, the design process becomes more responsive. This active participation empowers caregivers, reducing stress and enabling them to communicate their needs more effectively.[Lor23][SV22]

Furthermore, integrating feedback from stakeholders can uncover innovative solutions that are closely aligned with the realities of caregiving. This not only reveals implicit challenges—those that are not immediately obvious—but also directs attention toward new opportunities for improvement. By considering these perspectives, the design of Assistive Technologies can enhance usability and effectiveness, ultimately leading to better care outcomes.[Vas23][Sed16]

Thus, the application of Design Thinking in developing Assistive Technologies not only addresses the immediate challenges caregivers face but also fosters the creation of sustainable, user-friendly solutions that evolve alongside their needs over time.

#### Future Innovations and Directions in Assistive Technologies

Emerging trends in AT for caregivers, such as AI-based solutions utilizing machine learning or smart home technologies, hold significant potential to revolutionize caregiving by offering more adaptive and responsive solutions.[Lau24][Gib22] These innovations are expected to enhance caregiving efficiency and effectiveness, simplifying the management of responsibilities for caregivers while promoting a better balance between their own well-being and that of care recipients.[Ann20] However, to effectively leverage these advancements, it is essential to first understand the specific needs and requirements of family caregivers.[SV22] Therefore, this study will initially focus on Assistive Technologies in their most general form, without incorporating intelligent features. To gain a deeper understanding of the nature of support provided by family caregivers, a thorough analysis of their needs will be conducted. By clarifying these needs, future technological solutions can be more effectively aligned with the actual requirements of the study's target group.

In subsequent phases, the integration of Assistive Technologies could become increasingly relevant, particularly as Austria moves toward the digitalization of health data management. This potential integration with Austria's healthcare system – including electronic health records and telemedicine services – might offer significant benefits, such as enhanced care coordination and more personalized care. However, it could also pose challenges, including the necessity to ensure interoperability among various systems and the safeguarding of patient data.[Fed20]

### 2.3.4 Ethical Considerations and Legal Standards for Assistive Technologies

The implementation of Assistive Technologies in caregiving settings raises significant ethical and legal considerations that must be addressed to ensure the rights and welfare of both, caregivers and care recipients, along with all stakeholders involved.

#### Selected Legal and Ethical Issues

#### Data Protection and Privacy

The use of AT often involves the collection, storage, and processing of sensitive personal information, including health data and daily activities. Ensuring the privacy and security of this data is paramount, as unauthorized access or breaches could lead to misuse or exploitation. Caregivers and recipients must be informed about how their data will be used and the measures taken to protect it.[BMB<sup>+</sup>17][Bun09]

#### Informed Consent

Informed consent is a critical ethical requirement in caregiving and technology. Care recipients and their caregivers must be fully informed about the capabilities and limitations of Assistive Technologies, including potential risks and benefits. This transparency allows individuals to make educated choices about their use of these technologies.[BMB+17]

#### Autonomy and Dignity

The ethical principle of respect for autonomy emphasizes the importance of allowing individuals to make decisions regarding their care and the technologies they use. AT should enhance, rather than undermine, the autonomy and dignity of users. Hence, technologies should be designed to empower users, giving them control over their care processes by applying the principle of human-in the-loop.[Gó24]

In the context of dementia care, where recipients may struggle to fully comprehend their environment and surrounding actions, family caregivers may sometimes need to assume decision-making roles. This situation introduces a layer of complexity, as technologies must not only be designed to be bias-free but also allow family caregivers to make informed decisions based on certain data. Thus, a careful balance must be struck to maintain the autonomy of care recipients while supporting caregivers in their critical roles.[BMB<sup>+</sup>17][Bun09]

#### Selected Relevant Regulations and Guidelines in Austria

In Austria, several legal frameworks and ethical guidelines govern the use of Assistive Technologies.

#### General Data Protection Regulation (GDPR)

As part of the European Union, Austria adheres to the GDPR, which sets strict rules on data protection and privacy. This regulation mandates that personal data must be collected and processed lawfully, transparently, and for specific purposes.[AG24b][AG24a]

#### Austrian Digitalisation Report

This report outlines a strategy for digital transformation in the health sector in Austria and the use of digital health technologies, ensuring that patient data is handled in compliance with legal standards while promoting innovative health solutions.[Fed20] Thereby, a concrete information system is represented by ELGA, simplifying "the process of accessing the health records".[SCO24]

Austrian Federal Disability Equality Act [Bundes-Behindertengleichstellungsgesetz (BGStG)] This legislation aims to improve the participation of people with disabilities in all aspects of life. It emphasizes the need for equal treatment and the provision of appropriate aids to enhance quality of life.[Bun19] Therefore, while focusing on the needs of family caregivers, it is equally important to respect and ethically address the needs of care recipients in the development of technical solutions.

Addressing ethical constraints and legal considerations is essential for the responsible implementation of Assistive Technologies in caregiving. By adhering to relevant regulations and emphasizing ethical principles, it can be ensured that these technologies are used to enhance the quality of care while safeguarding the rights and dignity of all individuals involved. By incorporating these insights, Assistive Technologies can be designed to be both functional and aligned with ethical standards, ultimately leading to more effective support for all parties involved.

# 2.4 Concise Recap of Major Challenges Faced by Family Caregivers of People with Dementia in Austria: Emphasizing Research Relevance

Despite the various support structures discussed in earlier sections, family caregivers of PwD, the study's target group, continue to face significant and persistent challenges that impede the effectiveness of their care. This section will provide an overview of these key issues, in addition to those previously addressed, to emphasize the continued relevance of

this study. The objective is to highlight these ongoing difficulties before transitioning to the next empirical research section, the interviews.

# 2.4.1 The Unforeseen Role Transitions

Family members frequently find themselves unexpectedly or unprepared thrust into the role of caregivers, happening often during a pivotal life event. This unforeseen transition not only emphasizes the necessity for a standardized and efficient support framework but also underscores the critical role of time. Time constraints may limit their ability to acquire essential tools, knowledge, and appropriate support.[CL22][BD09][Ana23] Hence, numerous institutions relaized the importance of supporting family caregivers in early stages, and provide not only mental support but also materialize to train and sensibilze them on what dementia actually means and how to approach people with this impairment.

# 2.4.2 Financial Constraints and the Need of Fast Decision-Making

One of the primary obstacles faced by family caregivers stems from financial constraints, which further complicate both the overall caregiving process and access to professional care services. As the utilization of state-financed professional care services involves multiple levels of assessment before the case is approved, it does not guarantee immediate support. Consequently, family caregivers are compelled to make decisions, usually dictated by financial constraints—whether to engage private caregivers or undertake caregiving tasks themselves due to financial limitations.[BD09][AKAS<sup>+</sup>23]

# 2.4.3 Undervalued Role and Its Impact

Unfortunately, these scenarios are frequently overlooked or relegated to an informal role that evolves into an obligation without proper recognition. The repercussions of such circumstances are profound and significantly impact the physical and psychological well-being of family caregivers and their environment. [CL22] In literature, they are commonly depicted as "invisible second patients" or "informal caregivers" terms used to underscore their often-unacknowledged role in caregiving. [BD09] [GVKKS<sup>+</sup>23] [NCPSZ23]

These consequences initiate a cycle where their voices lack substantiated support, perpetuating a broader cycle of insufficient support for all stakeholders. In essence, the intricate interplay of financial, structural and acknowledgment challenges emphasizes the critical necessity for a thorough and targeted investigation. Such an inquiry is vital to enhance the support mechanisms for family caregivers, ensuring more efficient and tailored Assistive Technologies within the caregiving landscape.[FDO<sup>+</sup>23][GVKKS<sup>+</sup>23][Ana23] Hence, the study transitions to the first part, where family caregivers and other relevant stakeholders will be actively incorporated. This approach is intended to complement the findings of the current chapter with practical insights.



# CHAPTER 3

# The Voice of Family Caregivers and Experts

This chapter outlines the purpose and significance of conducting interviews involving people with lived experiences, family caregivers, and experts, emphasizing their critical role in identifying the needs and challenges faced by the study's target group. Interviews were selected as the primary qualitative research method due to their effectiveness in capturing in-depth insights into participants' experiences and behaviors.

These insights are crucial for establishing a comprehensive understanding of the specific requirements of the focus group of this research. Engaging directly with family caregivers allows for the revelation of distinct pain points, preferences, and expectations, which serve as foundational elements for developing relevant future technological solutions.

Furthermore, this qualitative approach incorporates a diverse range of perspectives from various stakeholders, facilitating a multifaceted understanding of the caregiving landscape. By analyzing these heterogeneous opinions, common themes and patterns can be identified, highlighting the unique and shared needs of family caregivers.

# 3.1 Introduction

Building on the discovery phase, this chapter transitions to the second step of the *Double Diamond Model*: the define phase, once all problems have been identified through the interviews. This can be seen in the upcoming figure, where the striped line, positioned near the end of the first phase, indicates the starting point of this chapter within the design model.



Figure 3.1: Double Diamond Model - Current Status within the Double Diamond Model *Source:* Created by Author based on Double Diamond Model by Design Council[Des24b]

Drawing from a comprehensive scientific foundation established in *Chapter 2*, this phase leverages firsthand insights into the thoughts, ideas, and behavioral patterns gathered from interviews. In this phase, the focus shifts from the broad exploration of diverse challenges faced by family caregivers to a more targeted synthesis of these insights.

To achieve this, a convergent approach is employed to distill key themes and define the precise needs of family caregivers regarding technical requirements. This process involves analyzing and organizing the varied data collected during the discovery phase, allowing for the identification of specific needs that should inform future technological solutions. Hence, by the end of this chapter, the second phase of the *Double Diamond Model* will be concluded, setting the stage for the third phase, where the generation of diverse solutions will be pursued through the Design Thinking Workshop.

#### Excursus: The Disconnect Between Innovation and User Needs: Importance of Requirements Engineering

Technical solutions designed for everyday use, aimed at solving real-world problems, often ignore or misinterpret the end user's real needs and requirements. Concrete examples supporting this argument can be associated with the rise of Internet of Things (IoT).[Cho20] [CCA19] Thanks to the multitude of data received through interconnected sensors, designers have had the opportunity to integrate functionalities in unique ways, attributing everyday objects with smart features.[Mio12] While the idea or intended purpose might seem reasonable, their realization and implementation often lack practicality and real added value.[Cho20]

Concrete examples of such products include the Toasteroid, promoted on Kickstarter as the first app-controlled smart image toaster, which burns the weather forecast onto toasted bread[Toa24], or the Quirky Egg Minder smart tray, which measures the freshness of eggs[Dig24]. Another example is Smalt, a smart salt shaker designed to track the amount of salt consumption, stream music, and enhance dining ambiance through integrated mood lighting.[Sma24]

Hence, to illustrate, the motivation behind providing weather forecasts is grounded in their importance for daily decision-making, such as dressing appropriately for the weather or choosing a mode of transportation.[Toa24] Given the fact that monitoring the weather forecast is commonly part of morning routines, integrating this functionality into a product that might be used during breakfast could seem logical. However, the practicality of such a combination is questionable, as not everyone has an appetite in the morning or time for breakfast. Thus, the effectiveness of this technology relies on conditions that may not consistently be present.

Discrepancies in innovation and real user needs, as presented in the excursus, highlight the critical need for rigorous analysis of the requirements of the study's target group. Ensuring that technological solutions are precisely aligned with their specific needs and demonstrate operational efficacy in their daily routines is essential.

Given that the research area was found to be underexplored and raised several fundamental questions – such as the basic requirements of family caregivers for technical solutions – a foundational baseline for the study needed to be established. To investigate their current situation and evaluate the availability, efficiency, and potential of Assistive Technologies, qualitative research methods were utilized. The interviews aimed to ascertain whether technologies specifically tailored for family caregivers are currently available, whether non-specialized technologies are being applied innovatively, or if there is any unintentional use of existing technologies. Additionally, the research explored the openness of family caregivers to adopting new technologies.

#### 3.2Methodological Framework for the Interviews

This section outlines the methodological framework utilized for conducting interviews. It addresses the interview design, participant selection, and recruitment strategies, including purposive and snowball sampling techniques, as well as the criteria for participant eligibility in the study.

#### 3.2.1Interview Design

The interviews, conducted in German, were designed as semi-structured conversations that permitted open-ended discussions while maintaining focus on specific topics of interest. This format proved particularly effective for exploring complex subjects, enabling a guided conversation that provided valuable insights into the potential of Assistive Technologies for family caregivers, along with the multifaceted challenges they face.

Interviews were conducted both online and in-person, depending on the preferences and schedules of the participants. This flexibility not only respected the individual circumstances of the interviewees but also ensured a more comfortable environment for sharing sensitive experiences.

In accordance with data protection practices, all participants were provided with a Participant Consent Form, outlining their rights and the nature of the study, which can be obtained in Appendix A.2: Interview Participant Consent Form.

#### Interview Approach

The interview process unfolded in two distinct phases. The first phase involved interviews with experts from various organizations and the public sector. This initial phase was crucial for sensitizing the interviewer to the broader context of caregiving in Austria. including existing support structures, future project initiatives, and the current level of technological integration within the caregiving domain. This foundational understanding informed subsequent interviews and allowed for more focused discussions with family caregivers.

The second phase comprised interviews with people with lived experiences, family caregivers. This two-step approach not only enhanced the interviewer's understanding of the subject matter but also allowed for the adaptation and validation of questions from an ethical perspective. By initially consulting experts, the interviewer could refine the inquiry process, ensuring that it was relevant to the needs of family caregivers.

#### **Guiding Interview Questions**

To ensure the acquisition of valuable insights, an *Interview Guide* was developed and validated from an ethical standpoint, as detailed in Appendix A.3: Interview Guide. The interviews were structured around specific topics designed to explore the experiences of the participants. Preliminary research on each interviewee's professional background and expertise informed the tailored questions, particularly for expert interviews.

36

Initially, the interviews commenced with an introduction to establish rapport and confirm consent for recording. Participants were invited to share their backgrounds, motivations for participating, and current roles in supporting family caregivers.

For expert interviews, the dialogue encompassed professional commitments and the role of technology. Specific inquiries addressed existing technological supports, successful case studies, challenges to acceptance, and potential future developments relevant to family caregivers of people with dementia. In addition, ethical considerations were a focal point, emphasizing responsible technology implementation. The importance of continuity in care, especially concerning multiple stakeholders, was also addressed. A further aspect included the exploration of feedback mechanisms, emphasizing the need for continuous input from caregivers and stakeholders to inform technological advancements. The necessity for interdisciplinary collaboration was similarly explored.

In interviews with family caregivers, the focus shifted to personal narratives that highlighted their challenges, the impact of technology on their caregiving experiences, and areas for improvement in support systems. This approach aimed to gather insights that would inform research objectives and the focus of the planned Design Thinking Workshop.

# 3.2.2 Interview Participant Selection

The selection of interview participants was guided by purposive and snowball sampling strategies [PHG<sup>+</sup>15], ensuring a diverse and representative sample of individuals with relevant experience and expertise in caregiving, particularly for individuals with dementia. These strategies effectively captured the perspectives of both family caregivers and associated stakeholders as experts, each contributing unique insights to the study.

#### **Purposive Sampling**

To select expert participants, purposive sampling was employed, involving the deliberate selection of informants based on their proven professional experience. [Rob14] Thereby, knowledge gained through initial research, presented in the *State of the Art* chapter, was utilized, alongside investigations into institutions and organizations actively involved in supporting family caregivers. The target group comprised researchers, domain experts, policymakers, healthcare professionals, and leaders in technological development for caregiving. These experts were chosen for their comprehensive understanding of the systemic factors influencing caregiving practices in Austria.

#### **Snowball Sampling**

Given the inherent challenges in accessing the primary focus group—family caregivers of individuals with dementia—snowball sampling was employed. This method is particularly useful in studies where the target population is difficult to reach, as it relies on referrals from initial participants to recruit others within their networks.[PHG<sup>+</sup>15] Hence, after conducting interviews with experts who often had connections to family caregivers, the

study expanded the participant pool by leveraging these networks, along with the author's personal connections.

#### Interview Inclusion Criteria

Participants were selected based on specific inclusion criteria established to ensure that the sample was relevant to the research objectives, as outlined below:

#### • Inclusion Criteria:

- Family Caregivers: Individuals who provide regular care for a family member with dementia in their immediate environment, maintaining a familiar or defined relationship, as outlined in the *State of the Art* chapter.
- **Experts:** Professionals whose work is related to family caregivers or the caregiving landscape in Austria.
- Health Condition of Care Recipient: Care recipients of family caregivers were limited to those with dementia to align with the study's focus.
- Residence: Both the caregiver and the care recipient resided in Austria.

By carefully considering these factors, the study aimed to achieve a balanced and representative sample, providing a solid foundation for the qualitative analysis of the caregiving experience and the potential role of technology in supporting family caregivers.

#### Interview Recruitment Process

The study utilized a multifaceted recruitment strategy that effectively leveraged both personal and secondary networks to identify potential participants. Additionally, information was gathered from various online platforms to locate relevant caregiving communities. Direct outreach efforts included emails, phone calls, and personal visits, while social media platforms like LinkedIn facilitated connections with professionals in the caregiving field.

Collaborating with relevant organizations and stakeholders allowed for the distribution of recruitment materials, such as flyers, within established caregiving networks. The recruitment text is available in *Appendix A.1: Official Interview Invitation and Participant Recruitment*, and its ethical appropriateness was validated by the study's ethical mentor and the *Unit of Responsible Research Practices at TU Wien*.

In addition, the author of the present study participated in three peer support gatherings:  $Café \ Dementi^{-1}$ , facilitated by Katharina Klee in an online format; Enthindert<sup>-2</sup>, also conducted online and led by Claudia Sengeis; and Café Zeitreise<sup>-3</sup>, held in person in

<sup>&</sup>lt;sup>1</sup>https://cafe-dementi.at

<sup>&</sup>lt;sup>2</sup>https://enthindert.blogspot.com

<sup>&</sup>lt;sup>3</sup>https://www.das-hufnagl.at/produkt-kategorie/cafe/

Vienna and led by Christoph Gstaltmeyr. These sessions provided valuable opportunities to engage with experts, family caregivers, and affected individuals. Prior consultation with the facilitators ensured that participation was acceptable to both hosts and participants. The interactions during these sessions not only enriched the study but also facilitated the identification and recruitment of family caregivers for interviews.

#### 3.2.3 Interview Data Collection and Analysis

Interviews were conducted both in-person and remotely, depending on participants' preferences and availability. Each session lasted approximately one hour, accommodating participants' schedules over a two-month period.

#### **Interview Data Collection**

Data collection was conducted using a smartphone for recording interviews, enabling precise transcription and detailed analysis that preserved the richness of qualitative data. The collected data was securely stored on a personal device, ensuring systematic management of transcripts, notes, and recordings. Transcriptions were thoroughly reviewed and anonymized to protect participant identities. Voice recordings, will be deleted upon completion of the study, while transcripts will be securely retained for future reference and validation of the research findings.

Data collection continued until thematic saturation was reached, indicating that no new themes emerged from the interviews, while respecting participants' availability and openness on specific topics. This approach ensured that the data comprehensively addressed the research questions.

#### **Interview Data Analysis**

The data collected from the interviews was analyzed using thematic analysis, a method particularly effective for identifying patterns and themes within qualitative data. This approach allowed for an in-depth exploration of various dimensions of caregiving, including key challenges, pain points, and the role of technology in supporting family caregivers. Thematic analysis involved coding the interviews to develop thematic clusters, which illuminated the primary challenges and opportunities identified by participants.[Sci24]

#### Limitations in Interview Data Collection and Analysis

While the study employed rigorous data collection and analysis methods, certain limitations should be acknowledged. The subjective nature of qualitative analysis may introduce researcher bias. Additionally, the depth and length of the interviews may have influenced the selection and scope of themes, which could, in turn, shape the future direction and focus of the study. Nevertheless, the structuring of themes was guided by the study's objectives and formulated research questions. These limitations should be considered when interpreting the findings that will be presented next.

# **3.3** Interview Findings and Discussion

The present section offers a detailed analysis of the conducted interviews with both, experts and individuals with lived experiences, which will be systematically presented.

#### 3.3.1 Interview Participant Numbers and Demographics

The interviews span a three-month period, from January to March 2024. Consequently, the interviews, particularly those with experts, that reference numerical data rely on the facts and information available up to that time.

Over the course of four interview rounds, a total of 6 experts – comprising 4 females (F) and 2 males (M) – provided valuable insights, representing a range of organizations such as: Interessengemeinschaft pflegender Angehöriger; the interdisciplinary Young Carers Project Team with professionals from FH Oberösterreich and Sozialministerium; Gesundheit Österreich GmbH (GÖG); and TU Wien, as shown in Table 3.1.

For completeness, while gender-related information is presented, the sample size does not allow for broader conclusions regarding gender-specific findings. Therefore, any mention of gender is limited to basic demographic representation and does not extend to an analysis of gender dynamics within the study's context – applying to the entire study.

Expert Interview Rounds	Participant Category	Role   Organisation
Expert Interview 1	Expert 1 (F)	Health Expert   Interessengemeinschaft pflegender Angehöriger
Expert Interview 2 Young Carers	Expert 2 (F)	Health Expert   Sozialministerium
Project Team	Expert 3 (F)	Health Expert   Sozialministerium
	Expert 4 (M)	Computer Scientist   FH Oberösterreich Campus Hagenberg
Expert Interview 3	Expert 5 (F)	Health Expert   Gesundheit Österreich GmbH (GÖG)
Expert Interview 4	Expert 6 (M)	Computer Scientist   TU Wien
Total Participants:	6 Experts	
		4 Health Experts
		2 Computer Scientists

Table 3.1: Expert Interviews in Overview

Further discussions, although not formally recorded, encompassed exchanges and personal visits with project leads at *Fonds Soziales Wien* and *Caritas Pflege*. These interactions significantly enhanced the depth of the present study and facilitated the refinement of a more structured research approach.

The following, *Table 3.2*, provides an overview of the 10 interviews conducted with a total of 12 family caregivers (FC) of people with dementia in Austria. The participants include a diverse group with varying backgrounds and relationships to the care recipients (CR). Specifically, the caregiver cohort includes 2 husbands, 3 sons, 5 daughters, 1 daughter-in-law, and 1 grandchild – comprising 7 females (F) and 5 males (M).

Family Caregiver (FC) Interview Round	Participant Category	Relationship to Care Recipient (CR)
Interview 1	Family Caregiver 1 (M)	Husband of CR
Interview 2	Family Caregiver 2 (F)	Daughter of CR
Interview 3	Family Caregiver 3 $(F)$	Daughter of CR
Interview 4	Family Caregiver 4 (M)	Son of CR
Interview 5	Family Caregiver 5 $(F)$	Daughter of CR
Interview 6	Family Caregiver 6 $(F)$	Daughter of CR
Interview 7	Family Caregiver 7 (M)	Son of CR
Interview 8	Family Caregiver 8 $(F)$	Daughter of CR
Interview 9	Family Caregiver 9 (M) Family Caregiver 10 (F)	Son of CR Daughter-in-law of CR
Interview 10	Family Caregiver 11 (M) Family Caregiver 12 (F)	Husband of CR Grandchild of CR
<b>Total Participants:</b>	12 Family Caregivers	
		2 Husbands 2 Song
		5 Daughters
		1 Daughter-in-law
		1 Grandchild

Table 3.2: Interviews with Family Caregivers (FC) of PwD in Overview

This representation highlights the familial dynamics present in caregiving situations, underscoring the range of perspectives shared by family caregivers during the interviews.

#### 3.3.2 Insights from Experts

Expert interviews played a pivotal role in the initial phase of understanding the challenges faced by family caregivers of people with dementia in Austria, as well as the different types of support available to them. Each expert brought valuable perspectives on the complex issues caregivers confront, with recurring themes such as the psychological burden of caregiving, societal stigma, and the potential role of Assistive Technology as a complementary support tool. These overlapping patterns will be in the present section highlighted.

#### Psychological Burden and Complexity of Caregiving

One of the most prominent themes from expert view that surfaced in the interviews is the overwhelming psychological strain, experienced by family caregivers. This mental burden often exceeds the physical challenges of caregiving, leading to high levels of stress, anxiety, and even burnout, as similarly discussed in Chapter, *State of the Art.* 

In Expert Interview 1, this issue was emphasized: "...eines der großen Problemfelder ist sicherlich die psychische Belastung für die pflegenden Angehörigen..., vergleichbar mit einer Mutter von kleinen Kindern, die sich auch Sorgen macht...".

Caregivers are often unable to mentally detach from their responsibilities, much like a parent who is constantly worried about the well-being of their child. This unceasing emotional weight compounds the isolation and fatigue many caregivers experience.

Adding to the psychological stress is the administrative and organizational complexity of caregiving. As the TU Wien Senior Scientist in Expert Interview 4 highlighted: "...meist landet all das Papierkramen und das Organisatorische bei den Angehörigen.".

This points to a larger issue: caregivers are often unprepared for the bureaucratic hurdles they must navigate, leading to feelings of overwhelm. Additionally, the expert further elaborated on the challenges caregivers face when trying to find the right resources: "...wo, wie, was, wo, wann, wie kann ich beantragen?".

This underscores a critical systemic gap in the support infrastructure for caregivers, indicating an urgent need for clearer guidance and streamlined processes to mitigate the time and effort expended in navigating bureaucratic complexities. By alleviating these administrative burdens, caregivers could allocate their resources more effectively toward direct caregiving activities, thereby enhancing the quality of care provided and optimizing the use of their available time.

#### Stigma and Acceptance of Dementia

Another significant theme identified in the interviews is the societal stigma associated with dementia, which often hinders timely diagnosis and access to support. According to Expert Interview 1: "Ein ganz großes Problem, das ich immer schon gesehen habe, ist eben, dass viele Menschen verständlicherweise aus Angst eine Diagnose gar nicht haben wollen und sich auch nicht untersuchen lassen.". The fear of diagnosis experienced by the affected individuals can prevent timely intervention and intensify the difficulties caregivers face in ensuring adequate care for the affected family member.

Furthermore, the expert emphasized that denial and a lack of acceptance of the condition complicate not only the caregiving process but also the recognition of family caregivers within society. "...da ist mir auch jetzt noch die Frage eingefallen, dadurch, dass die Krankheit an sich schon in erster Stelle nicht unbedingt als sowas aufgefasst wird von der betroffenen Person, dann kommt es noch dazu hin, dass zum Beispiel auch die pflegende Angehörige nicht so angenommen wird." (Expert Interview 1). Such a resistance often isolates carers even more, as they feel unsupported, invisible and face additional emotional challenges.

#### Young Carers and Shift in Roles

Beyond adult family caregivers, the interviews illuminated another important demographic: young carers, young individuals who take on caregiving responsibilities within their families. The demographic profile of young carers in Austria is striking. According to data discussed during the interview, 42,700 children between the ages of 5 and 18 are involved in caregiving: "was eben Young Carers angeht ... wurden erhoben, dass im Alter von 5 bis 18 Jahren, 42.700 Kinder pflegend sind..." (Expert Interview 2).

The most significant challenge in supporting this group is their lack of awareness about their caregiving role. As noted in Expert Interview 2, "Das Schwierige an der Situation ist, dass diese Kinder sich dessen gar nicht bewusst sind…". This invisibility makes it difficult for them to receive the support and recognition they actually need, both emotionally and practically.

Additionally, the interviews highlighted the complexities that arise from the role reversal in caregiving situations, particularly when a child becomes the caregiver for an elderly parent. As one expert noted: "...das große Problem ist ja auch, dass dabei ein Rollenwechsel stattfindet... weil jetzt plötzlich die Tochter, Sohn, wer auch immer, plötzlich aus der eigenen Kindheitsrolle heraus die Autorität übernimmt." (Expert Interview 1). This shift in family dynamics can lead to tension and conflict, as the caregiver takes on an authoritative role that disrupts traditional family hierarchies.

#### Gender Dynamics in Caregiving

Gender dynamics emerged as a recurrent theme throughout the interviews, with experts emphasizing that caregiving responsibilities often disproportionately fall on women.

As the expert on behalf of Interessengemeinschaft pflegender Angehöriger explained: "Und wenn jetzt mehrere pflegende Angehörige da sind, sind ja oft auch Familien, drei oder vier Personen, dann bleibt es meistens an einer Person hängen. Und das ist... die Frau..." (Expert Interview 1). This statement reflects broader societal expectations that caregiving is inherently viewed as a 'female responsibility', adding an additional layer of pressure on women. This imbalance is evident, not only among adult caregivers but also within the context of young carers. Among them, 70% are girls, many of whom dedicate up to five hours a day to caregiving tasks: "70% sind Mädchen. Das geht aber durch alle Gesellschaftsschichten durch... überwiegend Mädchen, die durchschnittlich 12,5 Jahre alt sind, und diese helfen ... bis zu fünf Stunden pro Tag. Das ist schon ganz erheblich." (Expert Interview 2). This gendered distribution of caregiving responsibilities places a disproportionate burden on young girls, underscoring the necessity for gender-sensitive interventions.

#### Dementia Strategy in Austria and Future Directions

Nevertheless, Austria's *Dementia Strategy* aims to improve the lives of people with dementia and their caregivers by coordinating efforts across healthcare professionals, government bodies, and researchers. As explained by the expert of  $G\ddot{O}G$  in Expert Interview 3: "Es hat 2014 einen Demenzbericht gegeben. Der war einmal die Grundlage für die Demenzstrategie. Und 2015 sind wir dann damit beauftragt worden, eine Demenzstrategie für Österreich zu entwickeln." This strategy is based on the, in 2014 issued, Dementia *Report* and has provided a framework for supporting both individuals with dementia and their caregivers.

An updated *Dementia Report* is scheduled for release in the last quarter of 2024, which will offer updated insights into the current state of dementia care in Austria. As the expert noted: "Heuer haben wir zum Beispiel den Demenzbericht überarbeitet... Der Demenzbericht, der wird im letzten Quartal 2024 veröffentlicht...." (Expert Interview 3). This forthcoming report is expected to address the gaps in the current strategy, with a renewed focus on supporting caregivers and enhancing care strategies across the country.

#### Expert Views on the Impact of Assistive Technologies in Caregiving

The role and perception of Assistive Technologies in caregiving were thoroughly explored during the discussions with experts.

Thereby, according to Expert Interview 4, while ATs play a vital role in supporting caregivers, they must be seen as only one component within a multifaceted system. The expert emphasized the tendency to overestimate the potential of technology to uniformly solve caregiving challenges, and highlighted the need for technologists to approach their work with greater self-awareness: "gerade als Techniker muss man ein bisschen selbstkritisch auch sagen... dass die Technik durchaus einen wichtigen Beitrag leisten kann, aber dass sie eigentlich ein Zahnrad ist in einem sehr komplexen System" (Expert Interview 4). This viewpoint encourages a more grounded and realistic understanding of what Assistive Technologies can achieve. While technology offers valuable tools, it cannot replace the human touch and personalized care required in caregiving, but rather complements these essential elements. It operates within a broader ecosystem that includes emotional, social, and financial dimensions among others. A purely technologycentric approach may overlook these essential aspects, leading to inadequate support for caregivers and care recipients alike.

#### Stakeholder Engagement and Interdisciplinary Approach in Dementia Care

A further relevant aspect is stakeholder engagement, which is a crucial factor in developing effective ATs. Inclusive design requires involving all relevant stakeholders, particularly caregivers, from the earliest possible stages of development. As the expert emphasized, for ATs to be effective, they must harmonize with each other: "mit den anderen Zahnrädern und anderen Akteuren gut zusammenarbeiten, gut harmonizeren" (Expert Interview 4). This means that technologies must align with the practical realities and needs of a broad spectrum of stakeholders, which can only be achieved by actively seeking and incorporating all perspectives and feedback into the design process.

Another aspect, however, suggests that the historical lack of integration of family caregivers in the design process has led to limitations: "Es geht eben natürlich zentral um den Menschen mit Behinderung oder mit Demenz oder einer chronischen Erkrankung. Das ist schon richtig, aber es gibt eben viele andere Akteure, und alle müssen gut zusammenwirken ... das ist vielleicht ein bisschen zu wenig passiert." (Expert Interview 4). This gap in involving family caregivers potentially results in the development of impractical solutions disconnected from real-world caregiving challenges. For Assistive Technologies to reach their full potential, this shortcoming must be addressed by fostering more collaborative and inclusive design processes that reflect caregivers' experiences.

While efforts have been made – not only in technical projects – to involve stakeholders, as patients, in the design process, as highlighted by the expert of  $G\ddot{O}G$ : "unsere Aufgabe im Rahmen der Demenzstrategie ist es, Stakeholder zu vernetzen… Das Ziel dieser Arbeitsgruppe ist vor allem, dass man Menschen mit Demenz eine Stimme gibt. Dass sie ihre… Bedürfnisse, ihre Anliegen irgendwie auch platzieren können." (Expert Interview 3), the active engagement of family caregivers remains limited. As the expert further noted, caregivers are often present, but more as companions to PwD: "…mit pflegenden Angehörigen eigentlich nicht. Wobei indirekt… In erster Linie, wir haben eine Arbeitsgruppe der Selbstvertretungen. Und in dieser Arbeitsgruppe der Selbstvertretungen sitzen Betroffene. Und diese Betroffenen, die haben Begleitpersonen mit, die aber nicht immer An- oder Zugehörige sind, sondern die kommen mitunter zum Beispiel von einer Selbsthilfegruppe… Das Wort gehört dem Betroffenen und nicht der Begleitperson." (Expert Interview 3).

This reflects opportunities for future engagement efforts aimed at enhancing caregiving procedures, where caregivers' valuable input—who play a vital role in daily care—may be better utilized. While affected individuals are rightfully prioritized in these discussions, it is also essential to create spaces where caregivers can contribute their insights and experiences directly. Doing so would provide a more inclusive view of the caregiving ecosystem and foster more comprehensive solutions.

An equally pressing challenge is the identification and engagement of young carers. These children and adolescents often do not recognize their role as caregivers, making it difficult for external support systems to reach them. As an expert described, "Unser Problem ist immer, an die Kinder heranzukommen. Und wie transportiert man das? Oder wie erhöht

man die Sensibilität für das Thema..." (Expert Interview 2). This lack of awareness often prevents young carers from seeking help, leading to a lack of support and, subsequently, limited ATs.

#### **Communication Barriers in Interdisciplinary Teams of AT**

Compounding the aforementioned challenges are the communication barriers that exist between interdisciplinary teams, particularly among technical and non-technical stakeholders when designing Assistive Technologies. As noted in Expert Interview 4, "man spricht zwar dieselbe Sprache... aber die Bedeutung der einzelnen Worte ist unterschiedlich" (Expert Interview 4). This statement underscores the critical need for clear communication and a shared understanding of terminology and goals among all parties. Misunderstandings can arise even when the same words are used, due to differences in interpretation between engineers and caregivers, for instance. Bridging these gaps is essential for fostering more effective collaboration by applying suitable research and communication methods.

A successful project by an interdisciplinary team is exemplified by the Young Carers Project Team, who developed a final product; a mobile app, and subsequently a website tailored for young carers. This initiative highlights how technological innovation can effectively meet specific caregiving needs, leveraging the expertise of both, technology and health experts. As noted in Expert Interview 2: "hat angefangen mit der Entwicklung einer App. Wir haben mittlerweile eine Homepage", demonstrating their expanded portfolio, which enhances resource accessibility for young carers.

However, despite these advancements, the broader assistive technology market continues to face significant barriers in translating research-based solutions into practical, everyday applications.

#### Research and Development of AT: Translating Innovation into Practical Solutions

While research in Assistive Technologies has made significant strides, a substantial gap remains between the development of prototypes and the availability of marketready products. According to Expert Interview 4, this issue has been highlighted: "nach eigentlich fünf, zehn, 15 Jahren Forschung in diesem Bereich... erstaunlich wenig wirkliche Produkte dann irgendwie jetzt verfügbar". This disconnect between research and commercial application underscores the need for a more strategic approach to translating innovative research into products that caregivers can readily access and use in their daily lives.

Despite these challenges, the expert remains hopeful about the future of Assistive Technologies, emphasizing their potential to become a central element: "ein durchaus wichtiges, möglicherweise wahrscheinlich wichtiges Zahnrad" (Expert Interview 4), within caregiving systems. For this vision to become a reality, ongoing efforts must focus not only on technological innovation but also on ensuring that these tools are accessible,

46

effective, and seamlessly integrated into the lives of care recipients, caregivers—both formal and informal—and other stakeholders.

In summary, the expert interviews provided a nuanced understanding of the challenges faced by family caregivers of individuals with dementia in Austria from an expert perspective. The psychological strain and complexity of caregiving, coupled with societal stigma and the often under-recognized role of family caregivers, especially young carers, underscore the urgent need for more comprehensive and targeted support systems. Additionally, gender dynamics further complicate caregiving responsibilities, disproportionately impacting women and girls. While Austria's *Dementia Strategy* serves as a promising framework, it must continue to evolve to effectively address these critical issues. The upcoming version of the *Dementia Report* is poised to be a vital resource in advancing these efforts, ensuring that caregivers receive the practical and emotional support they need.

Assistive Technologies have been explored as potential supplements to address specific caregiving needs. All experts expressed a general openness to future innovations in this field. However, several potential challenges were highlighted, particularly communication barriers between technical and non-technical stakeholders. This underscores the critical need for clear and constructive dialogue. Successful projects, like the Young Carers Project, demonstrate how interdisciplinary teams can develop practical solutions, yet challenges persist in translating research into accessible products. Despite these obstacles, there is hope for the future of ATs to play a central role in caregiving, provided that ongoing efforts ensure their accessibility and effectiveness for all involved.

# 3.3.3 Insights from Family Caregivers of People with Dementia

In the course of the interviews, family caregivers embraced the chance to discuss their insights, driven by a shared recognition that caregiving demands greater attention and understanding.

As one caregiver noted: "Der Punkt eins ist, ... das ist ein Thema, ... wo wir zu wenig darüber reden." (Family Caregiver 1), emphasizing how caregiving remains underrecognized. This reflects the common feeling of invisibility caregivers experience, despite the immense organizational and physical burden of their roles.

Participants also highlighted the importance of peer support in reducing the isolation they often face. As one participant noted: "Und ja, der Austausch ist ja nicht schlecht, wenn man mit Leuten darüber spricht." (Family Caregiver 6).

Beyond personal motivation, some caregivers felt a responsibility to contribute to the larger societal conversation. One said: "Zum einen, weil ich es großartig finde, wenn Studierende sich mit einem spannenden Thema auseinandersetzen ... Die zweite natürlich, um das wichtige Thema voranzubringen, auch wir stehen vor einer großen Pflegeherausforderung der Zukunft." (Family Caregiver 8). This reflects not only personal concern but also recognition that caregiving is a societal challenge demanding urgent attention and action.

Throughout the interviews with all 12 participants, distinct recurring patterns emerged, illuminating the shared challenges encountered by family caregivers of PwD in Austria.

These themes will be presented in a structured format to provide a comprehensive analysis of the caregiving experience and to explore the potential role of technology in enhancing the caregiving ecosystem.

#### Initial Obstacles in Identifying the Right Resources

A prominent challenge identified by family caregivers is the difficulty in quickly locating appropriate resources, particularly in the early stages of caregiving, when roles remain undefined and unfamiliar. One caregiver stated: *"Es war schwierig, die passenden Informationen zu der Zeit zu finden."* (Family Caregiver 1). Despite the existence of various supporting frameworks – as confirmed by experts – there remains a critical need for systematic support to navigate the initial phases of caregiving. Timely and clear access to relevant resources is essential, particularly as caregivers frequently encounter rapidly changing circumstances.

One participant suggested that technology could enhance this process by offering a comprehensive information package: "Einfach eine Info-Mappe, Info-Datei, wo man einfach sieht, was man alles machen kann, wann was möglich wäre." (Family Caregiver 3). Such a solution could address primary questions and concerns, helping caregivers manage the overwhelming influx of information.

However, in urgent situations, reliance on technology may be insufficient. As another caregiver expressed frustration over the lack of immediate guidance in such settings, stating: "... ich suche gerade, ich vermisse extrem, sehr extrem, eine Anlaufstelle für pflegende Angehörige, eine Anlaufstelle für... die sehr kompetent und hilfe orientiert den Angehörigen in bestimmten Situationen, in den Notfallsituationen helfen. Ich möchte fast sagen, eine Angehörigen-Demenz-Hotline." (Family Caregiver 1). The call for an "Angehörigen-Demenz-Hotline" underscores the urgent need for direct communication lines, enabling caregivers to seek immediate advice and personal assistance, particularly in crises situations.

#### Fluctuation in Daily Habits and Family Dynamics

Caregivers frequently face challenges in managing daily routines, largely due to the unpredictable nature of the care recipient's health condition, especially in cases of dementia as many reported. One caregiver illustrated this unpredictability in response to a question about what an average day in caregiving looks like, stating: "Die erste Antwort auf diese Frage ist, der typischste Tag ist jeder Tag. Ich weiß um sieben Uhr nicht, was mich um viertel acht erwartet. Und das möchte ich für die letzten fünf Jahre so stehen lassen." (Family Caregiver 1). While another family caregiver reported: "Naja, ich glaube, es ist schwierig. Was zum Beispiel sehr schwierig ist mit einem Menschen [PwD, care recipient], ist, eine Tagesstruktur aufrechtzuerhalten. Und dann den Ablauf." (Family Caregiver 5). Such irregularities in caregiving creates substantial physical and emotional demands, compelling caregivers to continually adapt to the evolving needs of care recipients.

This necessity for flexibility emerged as a key theme in the interviews. Consequently, caregiving environments underscore the requirement for solutions that effectively address these fluctuations, particularly in the design of Assistive Technologies that assist family caregivers in managing daily care routines.

Thereby, maintaining open lines of communication within the family is essential and represents a further aspect to promote in future Assistive Technologies, particularly in navigating the unpredictable nature of needs in care.

One caregiver highlighted this dynamic, stating: "Es ist ein ständiger Kontakt mit eigentlich allen Familienmitgliedern, mit ihren Kindern, Schwiegerkindern, Enkelkindern, Urenkelkindern." (Family Caregiver 2). On this note, ongoing interaction fosters a support network capable of adapting to the care recipient's changing needs. Furthermore, it ensures shared responsibilities and prevents any single family caregiver from shouldering the entire burden alone.

Besides effective communication, the establishment of defined roles within the family is another crucial factor. When a collaborative approach is possible, the efficiency of this strategy often depends on the clear distribution of caregiving tasks among family members. A well-organized structure can be attained through the following statement: "Wir haben intern in der Familie aufgeteilt, ich bin für die Finanzen zuständig, meine eine Schwägerin ist für medizinische Sachen zuständig, und die dritte [name of the third person] ist so, ... die Springerin, die Allrounderin ..." (Family Caregiver 2). This clear division of responsibilities ensures that each family member has an understanding of their specific role, allowing for efficient task management. As the caregiver further explains: "Das wissen die Pflegerinnen auch: wenn irgendwas Medizinisches ist, wenden sie sich an meine eine Schwägerin; das mit den finanziellen Sachen wenden sie sich an mich; ... und wenn sonst irgendwas anderes ist, können sie [name of the third person] direkt ansprechen. ... Also es ist wirklich so, die verschiedenen Bereiche haben wir von vornherein zugeteilt und ja, da herrscht auch Vertrauen." (Family Caregiver 2). This structured approach not only facilitates smooth caregiving operations but also reinforces a cooperative family dynamic, minimizing potential conflicts, confusion or overlap in caregiving duties.

However, collaborative care is not a feasible option in all family environments due to factors, such as geographical separation or differing levels of availability. Consequently, in many instances, caregiving responsibilities fall disproportionately on a single individual, which can complicate family relationships and create significant emotional and logistical strain. As one caregiver stated: "Leider Gottes bleibt alles so ziemlich an mir hängen." (Family Caregiver 3). Another echoed this sentiment: "Ich mache alles alleine." (Family Caregiver 1). A further interview participant emphasized similar concerns: "Naja, mehr mache ich, mehr mache ich..." (Family Caregiver 6). This imbalance intensifies the challenges of caregiving, often leaving the primary caregiver overwhelmed by the combined physical and emotional demands.

In this context, the development of technologies that leverage digital connectivity could be crucial for optimizing task distribution and management among various stakeholders. This is particularly relevant as solutions and administrative processes – such as the primary application process for care allowance – increasingly offer digital management options. By enabling real-time collaboration and resource sharing among family members, these future Assistive Technologies have the potential to greatly enhance overall caregiving efficiency and strengthen the support network for care recipients.

#### Time Management and Organization as Key Players

Efficient task distribution is essential in creating a balanced caregiving environment, as argued in the previous sections. Family caregivers, especially in demanding situations, must develop strong time management and organizational skills and practices. This need was underscored during the interviews, with caregivers sharing various approaches to managing caregiving responsibilities.

One family implemented a hybrid model, using a paper-based weekly calendar template to coordinate visits to the care recipient. A photo of this template was shared in the family's WhatsApp group, along with a request for family members to adjust their availability as needed and send it back for final coordination. The figure below illustrates a version of a customized template with the availability of family members.



Figure 3.2: Customized Hybrid Time Management Tool Source: Provided by Family Caregiver 2

Another family adopted a fully digital solution, utilizing a shared digital calendar to track care availability and absences. As one caregiver explained, "... Kalender, der da am Handy ist und mein Kind hat das gemacht, ..., ich kenne mich überhaupt nicht aus mit diesen Sachen, ..., dass ich da jetzt am Tag eintragen kann und sie sieht das, was ich eintragen habe... es ist eh ein gutes Werkzeug." (Family Caregiver 5). According to this caregiver in further discussions, the digital calendar has proven to be effective for coordination, as it provides valuable information regarding availability and notes on specific days of absence.

Caregivers also expressed interest in tools that could further assist with daily scheduling and task management, such as virtual checklists or To-Do lists. One caregiver noted the usefulness of such technology for maintaining structure in an otherwise unpredictable daily 'routine': "Genau, ja. So etwas wäre wahrscheinlich schon hilfreich [referring to a digital checklist or To-Do List]. So etwas, das man verwenden kann. Ich habe das Gefühl, dass das ein besonderes Problem ist. Dass der Mensch selber ja Raum und Zeit verloren hat. Er weiß nicht, ob es in der Früh, am Abend oder mittags ist. Und auch die Motivation. Also dem Menschen fehlt ja die Motivation, etwas zu tun." (Family Caregiver 5). In addition to its potential, the concern regarding declined motivation has been underscored. This observation identifies a critical area for further exploration in the design of Assistive Technologies, particularly concerning the application of gamification principles in shared tools to enhance user engagement and motivation.

On a further note, a purely paper-based calendar proved to be inefficient in the context of one interviewee's situation, as the care recipient experienced significant frustration upon viewing the scheduled appointments. These appointments, which included essential visits from professional caregivers among others, were often those that the care recipient preferred to avoid. Resulting in increased discussions between the married couple. As indicated by the following statement from the perspective of a grandchild: "...Das Problem ist, wenn die Großmutter diesen Kalender sieht, dann kommt es zu einer Diskussion, die für dich wahnsinnig anstrengend ist" (Family Caregiver 10). The primary caregiver further remarked, "Jetzt schaut sie nicht mehr hin, aber das wars...[referring to the exhausting arguments]." (Family Caregiver 9).

Hence, the previously highlighted methods of organizing care within families suggest the need for further investigation, as recurring patterns of well-established solutions were not identified, irrespective of the nature of the calendar utilized.

#### Documentation and Continuity in Caregiving

The challenge of navigating financial support systems, such as the Austrian government's care allowance, was a recurring theme during interviews with caregivers. Many caregivers expressed frustration with the complexities of the application process, particularly in understanding eligibility criteria and documenting care activities. One caregiver remarked, "...verrechnest du viel, musst dreimal anrufen, kommst nicht durch." (Family Caregiver

6), underscoring the bureaucratic inefficiencies that further complicate the process of securing financial support.

Consequently, a family caregiver suggested the potential usefulness of a digital checklist or guide, stating, "So ein Wegweiser oder so eine digitale Checkliste könnte eventuell überlegenswert sein" (Family Caregiver 1). This reflects an increasing awareness of the need for digital resources to simplify the application process, providing clearer guidelines for eligibility and required documentation.

In another instance, a caregiver emphasized the importance of integrating calendar functionalities into such tools, suggesting that a system enabling quick data retrieval could further ease the documentation process: "Ich glaube, diese Dokumentationsmöglichkeit sollte tatsächlich mit Kalenderfunktion da sein... Wenn ich einfach auf Knopfdruck habe, die Daten, wo ich bei ihr war." (Family Caregiver 7). This highlights the potential for a well-organized care documentation platform to streamline caregiving tasks, by allowing caregivers to efficiently extract their activities from connected calendars with minimal effort.

A central theme that emerged, was the demanding task of documenting care hours and activities, often in the form of a care diary. This documentation is essential for determining the appropriate level of care intensity when applying for care allowance. While some caregivers only recognized the value of such documentation retrospectively: "Nein, haben wir nicht gemacht. Wäre aber sicher sinnvoll gewesen." (Family Caregiver 7), others actively adopted this practice after encountering difficulties.

Explaining: "Naja, wir haben ein Pflegetagebuch normalerweise nicht geführt, aber weil wir wissen, dass es bei der [name of the health insurance institution] Schwierigkeiten gibt und dass man das genau dokumentieren muss..." (Family Caregiver 4). To address this need, the caregiver highlighted the use of the platform Alles Clara, a digital solution for recording care activities in detail: "Da gibt es ja die Plattform, die heißt Alles Clara... und da ist wirklich, wie minutiös kann man da eintragen, Pflegeschritte für jeden Tag." (Family Caregiver 5). To convey an impression of the tool, the interviewee provided an extract, which is shown in the following illustration.

52

Aktivitäten und Hilfsleistungen			eme		Bitte die ungefähre Dauer in Minuten eintragen					
	Anleitung	Unterstützung	Teilweise Übernah	Volle Übernahme	Morgens	Mittags	Nach- mittags	Abends	Nachts (22:00-06:00)	Notizen
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Ganzkörperwäsche										
Teilwäsche	×	×	X		20			20		
Duschen										
Baden										
Zahn- / Mund- /	4	1			T			5		
Prothesenpflege	X	X			5			5		
Frisieren	X	X			5			5		
Rasieren										
Haare waschen										
Ankleiden	X	×	X		20					
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Maniküre										
Pediküre										
Kanülen-Pflege										
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/Stuhlprophylaxe	N.	X					20			
Reinigung		1	1		1					
Leibstuhl/Harnflasche				Х	10					
Wechseln von	1		V		_		-	_		
Inkontinenzmaterial					5		5	5		
Stoma-Pflege										
Dauerkatheterpfiege										
Ernährung		100								
Zubereitung Nahrung				Х	10	20	10	10		
Mundgerechte										
Verarbeitung										
Nahrungsaufnahme	X				5	5	5.	5		
Sondennahrung										
Sonden-Pflege										
Medikamenten-einnahme	X	X			10			10	1	
Mobilität						the state of the second				
Aufstehen vom Bett	X	X			20					
Positionswechsel	武	×			· ·	5	B	15		
Stehen										
Gehen / Bewegen	X	X			S	5	5	5		
Treppensteigen										
Wohnung verlassen				X						
Terminbegleitung				X						
Hilfe mit Rollstuhl	Ľ			X						I
Hauswirtschaftliche V	erso	orgi	ung							
Einkaufen				X			80			2 x wochently
Besorgung Medikamente				X			30			1 x monote
Vorbereitung				v			2.			1
Medikamente				$\wedge$			50			1 x Wochenk
Wäsche waschen				X			30			2x Wochenk
Reinigung Wohnung				X			180			1x warent
Reinigung Geschirr				X	10		20	10		
Wohnung beheizen	1	1					1			

Figure 3.3: Alles Clara - An Excerpt from the Care Diary Source: Provided by Family Caregiver 5

The platform delivered templates and enabled them to document key care procedures, from daily care routines to the involvement of external care providers, providing comprehensive data for their application. On a further note, the user emphasized the platform's effectiveness, stating, "Ja, die App ist sehr gut, ja." (Family Caregiver 5).

In conclusion, while the process of applying for financial aid remains a significant burden due to bureaucratic complexities and unclear requirements, the adoption of digital tools offers a promising avenue for simplifying caregiving documentation. By providing clear, structured guidance and reducing the administrative workload, these tools have the potential to improve both the caregiver's experience and efficiency in caregiving practices.

#### Technological Presence in Caregiving and Future Ideations

As emphasized in the preceding sections, the presence of technology, along with the potential and desire for specific future advancements, has been consistently identified throughout the interviews based on participant reports.

In addition to previously discussed digital tools such as digital calendars and care documentation platforms like Alles Clara, caregivers reported utilizing another essential technological resource aimed at enhancing communication and coordinating visits among family members: WhatsApp. This application is recognized for its user-friendly features, which facilitate the creation of group chats and enable efficient sharing of multimedia content, including photographs and documents.

A significant proportion of family caregivers indicated regular utilization of WhatsApp as an effective communication platform: "Ja. Wir sind in der Familiengruppe, in der WhatsApp-Gruppe dabei, beisammen." (Family Caregiver 1). Another family caregiver similarly reported the utilization of the tool among family members: "... haben wir eine WhatsApp-Gruppe auch über die Enkelkinder gemacht." (Family Caregiver 2)

However, some caregivers noted that the effectiveness of WhatsApp can diminish over time, highlighting potential challenges related to user engagement and communication continuity: *"Wir haben das vor, vor einem Jahr, nachdem er aus dem Spital gekommen ist, ins Leben gerufen... aber das hat sich, ist dann ziemlich eingeschlafen."* (Family Caregiver 4).

These observations emphasizes the need for ongoing evaluation and the development of strategies to enhance the sustained effectiveness of digital communication tools within caregiving contexts. Additionally, further pathways may warrant exploration regarding their integration into a complex caregiving ecosystem. A tool utilized on a daily basis could offer, in addition, opportunities for expanding care diaries by integrating content in an automated manner through the application of machine learning algorithms. Inspired by a study published by "Laurentiev et al. (2024)", which used a machine learning model to assess activities of daily living (ADL) and instrumental activities of daily living (iADL) impairments from "electronic health record clinical notes". [Lau24] This approach showcases the potential of advanced data analysis in healthcare.

During the interviews, participants were also asked to share ideas about future Assistive Technologies, with several innovative ideas.

One family caregiver expressed optimism about the potential for improving access to health records through digital integration. The participant envisioned a system where health records and care monitoring tools are seamlessly connected, allowing for easier access and more coordinated care: "Die Gesundheitsakte und E-Card, dass man das schnell abrufen kann von Betroffenen... das wäre vielleicht eine Möglichkeit." (Family Caregiver 4). This forward-thinking perspective reflects a future, in which caregiving could be more efficient and less bureaucratic, with technology enabling quick access to vital health information.

A further interviewee also identified the potential of technology to support elderly individuals in maintaining independence. Simple, user-friendly applications could provide step-by-step guidance for daily activities, helping older adults remember essential tasks such as brushing their teeth. As a result, repetitive and tiring processes for family caregivers may be reduced. Stating: "Naja, ich habe mir eigentlich gedacht... der Mensch vergisst ja, wie er was machen soll. Solange es nicht ein ganz extremes Stadium ist, würde ihm vielleicht helfen... Applikationen, wo er sich Abläufe anschauen kann... Zähneputzen, dass die nicht immer alles fragen müssen." However, the caregiver noted that adoption might be challenging for PwD, depending on the stage of cognitive decline: "Aber ich weiß nicht, ob es da Applikationen zum Beispiel gibt." (Family Caregiver 5). This statement reflects the growing interest in Assistive Technologies that support daily living, though it also underscores the potential difficulty in introducing such tools to older adults with advanced cognitive impairment.

Such a remark necessitates incorporating a human touch alongside technological advancements, through a Human-in-the-Loop (HITL) approach.[Gó24] This perspective can also be obtained from a family caregiver with a technical background, who emphasizes the importance of human involvement in caregiving, as follows: "Also ich selbst war Programmierer vom Beruf. Und, wenn ich sehe, was technisch alles möglich ist, bin ich überzeugt davon, dass da eine gut gemachte App durchaus weiterhelfen kann. Aber, und auch das ist meine felsenfeste Überzeugung, irgendwo sollte trotzdem immer ein Mensch dahinterstehen." (Family Caregiver 11).

Hence, participant interviews revealed a general openness and creative ideas regarding how technology might be leveraged according to their specific caregiving contexts. Caregivers expressed enthusiasm for integrating digital tools to enhance communication, improve access to health information, and support daily living activities, among others, while also recognizing the importance of maintaining a human element in the caregiving process.

# 3.4 Conclusion

The overall design of the interview process aimed to elicit comprehensive insights into the caregiving experience. By employing a semi-structured format, participants were encouraged to share their unique narratives, fostering a richer understanding of the intersection between caregiving and technology.

Challenges in reaching interview participants, particularly family caregivers – who often face time constraints and sensitive situations – were evident. However, both family caregivers and experts demonstrated a high level of engagement and a willingness to openly discuss their experiences. This openness suggests significant opportunities for integrating first-hand insights into innovative solutions for future ATs within caregiving practices.

Thereby, the conducted interviews underscored the need for a high level of empathy, flexibility, and transparency in dealing with participants, many of whom feel social isolation.

As indicated at the beginning of the present chapter, the completion of the interview analysis fulfills the objectives of the second phase of the *Double Diamond Model*, as depicted in the figure below. This stage involved attaining the interview findings and synthesizing them to enhance the overall understanding of the research topic.



Figure 3.4: Double Diamond Model - Phase 2: Define Source: Created by Author based on Double Diamond Model by Design Council[Des24b]

Paving the way for the third phase, where a range of solutions will be developed as part of the Design Thinking Workshop.
# 3.4.1 Overview of Selected Themes Emerging from Interviews

The analysis of the interviews revealed a variety of pressing challenges and needs that significantly impact family caregivers' situation of PwD in Austria. These themes reflect the multifaceted nature of caregiving, encompassing emotional, logistical, and systemic issues, among others.

- **Resource Identification Challenges:** Caregivers often struggle to quickly and efficiently identify the appropriate resources and support systems available to them, particularly during the early phases of their caregiving journey. This can lead to feelings of frustration and isolation.
- **Time Management Difficulties:** Many caregivers face significant time management challenges, particularly in balancing caregiving responsibilities with personal and professional commitments. This includes the complexities of managing family dynamics when distributing tasks among family members.
- **Involvement of Young Carers:** The role of young carers, who are often overlooked in discussions about caregiving, merits future investigation. Understanding their unique challenges and contributions can inform better support systems for all caregivers.
- Financial Support Application Issues: Navigating the complexities of financial support applications, such as the care allowance provided by the Austrian government, poses significant challenges. Caregivers often find the application processes and required documentation overwhelming and confusing.
- Lack of Comprehensive Information: There is a limited and often fragmented overview of available knowledge bases, resources, and hotlines that can provide quick and reliable information for caregivers. This gap complicates caregivers' ability to access timely support and information.
- Mental Health Challenges: Maintaining mental well-being while providing effective support to the care recipient is a common struggle. Caregivers frequently report feelings of stress, anxiety, and burnout due to the demands of caregiving.
- Communication Barriers: Caregivers often experience difficulties in communicating effectively with family members, healthcare professionals and/or other stakeholders. This can lead to misunderstandings and a lack of coordination in care efforts.
- Social Isolation: Many caregivers feel socially isolated due to the demands of their caregiving role. This isolation can exacerbate mental health issues and limit opportunities for support from peers.

- **Training and Skill Development Needs:** There is a recognized need for training and skill development among caregivers, particularly in areas such as medical care, emotional support, and crisis management. Caregivers often feel unprepared for the diverse challenges they face.
- Gender Imbalance in Caregiving Roles: The gender imbalance among caregivers is a significant issue, with women often bearing a disproportionate burden of caregiving responsibilities. This theme highlights the need for future exploration of how gender influences caregiving dynamics.

Understanding and acknowledging these themes is crucial for informing the development of effective support mechanisms and interventions.

#### 3.4.2 Ethical Considerations in Light of Interviews

Ethical considerations were paramount throughout the study, shaping every aspect of the research process. Participants were fully informed about the study's purpose, procedures, and their rights. This transparency fostered trust and ensured informed consent for all recordings, which were crucial for accurate data collection. Ethical mentorship validated the processes, including participant recruitment, interview questions, and participant consent.

The audio recordings of interviews facilitated precise transcription and analysis, preserving the richness of participants' responses. Maintaining confidentiality was a priority, leading to the rigorous anonymization and secure storage of all data. Upon completion of the study, voice recordings, will be deleted, while transcripts will be securely retained for future reference and validation of the research findings.

To uphold ethical standards, individuals with dementia and young carers were intentionally excluded from the interviews. This decision was based on the need to protect sensitive populations. Nevertheless, the study recognizes the importance of including a diverse range of stakeholders in future designs of Assistive Technologies.

#### 3.4.3 Potential Biases

While the interview process was carefully managed to minimize observer bias, several potential biases were identified and addressed:

• Sampling Bias: The use of snowball sampling, while effective in recruiting participants, may have led to a sample that does not fully represent the broader population of family caregivers. However, efforts were made to include a diverse range of caregiving scenarios, including those providing care at home and those navigating professional care settings.

- Selection Bias: The purposive selection of experts may introduce bias if preconceived notions influence the identification of who qualifies as an expert, particularly given the large number of organizations involved in this domain. This concern is exacerbated by time constraints and limited availability of qualified professionals. To mitigate this risk, well-defined selection criteria were established, ensuring that participants from diverse and relevant sectors were included. This approach acknowledges the contributions of a broader array of organizations dedicated to enhancing the well-being and support of family caregivers.
- **Thematic Analysis Bias:** The study acknowledges that the extensive volume of input material may introduce certain biases in the selection and categorization of themes.

In conclusion, the interviews revealed that a semi-structured format of the conducted interviews is effective, allowing for a common understanding of the needs and requirements coupled with expert input. With this knowledge and insights gathered, the Design Thinking Workshop will incorporate the points highlighted in the interview findings.



# CHAPTER 4

# Design Thinking Workshop

The Design Thinking Workshop forms the core of the present study, designed to deepen the understanding of user requirements in a co-design manner, with the goal of exploring potential solutions for family caregivers of individuals with dementia in Austria. By applying *Design Thinking (DT)* principles, the workshop facilitates a structured collaboration between family caregivers and experts to identify and address key needs, motivations, and challenges.

Building on insights from prior interviews and the literature review, this approach refines the understanding of caregivers' pain points, guiding the creation of targeted, practical solutions. Thereby, the process is designed to ensure, solutions are both, relevant to real-world caregiving scenarios and feasible for implementation.

The workshop's outcomes are further analyzed from a technical perspective to extract insights that inform future technological development, promoting the practical implementation of the proposed solutions in advancing Assistive Technologies.

# 4.1 Introduction

Developing accessible and user-centered Assistive Technologies, necessitates a thorough investigation of key challenges and the associated needs of users. In this context, *Design Thinking* serves as an effective research method, by integrating active user feedback into scientific approaches, facilitating a co-design process. By prioritizing innovation, experimentation, creativity, and prototyping within an interdisciplinary and collaborative setting, Design Thinking as a research tool empowers participants to address complex problems effectively.[SV22]

Thereby, the framework of DT is structured around five distinct phases according to literature as follows: *empathize*, *define*, *ideate*, *prototype* and *test*.[SV22] By leveraging the first four phases – excluding the final phase, which will be elaborated on later – and instrumental principles of Design Thinking, this workshop aimed to generate deep insights into the needs, motivations, and pain points of family caregivers.

In a broader context, this chapter transitions from the second phase of the *Double Diamond Model*, which focused on defining the problem space through the insights gathered from the interviews, this chapter now moves into the *develop phase*, as presented in the figure below.



Figure 4.1: Double Diamond Model - Phase 3: Develop Source: Created by Author based on Double Diamond Model by Design Council[Des24b]

In this regard, the third phase is represented by the Design Thinking Workshop, which emphasizes collaborative exploration and solution generation. Adopting a divergent approach, this phase promotes a diverse array of ideas to effectively develop solutions. From the interviews conducted, several key problem areas surfaced that illuminate the challenges faced by family caregivers, summarized as follows:

- Obstacles in identifying the right resources for family caregivers quickly and efficiently, especially in the early phases of the caregiving journey.
- Time management challenges and the complexities of managing family dynamics in distributing tasks, as well as handling daily duties.
- Difficulties in applying for financial support, such as care allowance granted by the Austrian government, and navigating the complexities of the application process and required documentation.
- Limited comprehensive overview on; knowledge bases, and hotlines for quick information acquisition.
- Difficulties in maintaining mental well-being while providing effective support to the care recipient.

These identified problem spaces will be systematically addressed within the distinct focus groups, where opportunities for collaboration between family caregivers and experts with specialized domain knowledge will be facilitated.

The tangible outcomes emerging from these focused discussions will not only further clarify the needs of family caregivers but also provide a comprehensive understanding that builds on insights from the initial interviews and literature review.

This research method offers participants a platform to articulate their requirements and aspirations for future technical solutions, as well as areas where they seek additional support, regardless of the technical feasibility of such implementations. By synthesizing these findings, clear connections can be drawn between the insights gained and their implications for enhancing existing technologies and guiding future innovations in caregiving.

To maintain the technical focus of the present study, each focus group will be oriented around technology-affine topics, facilitated – where possible – by experts with relevant technical understanding and expertise. This strategic alignment ensures that the solutions developed will not only be practical, reflecting their technical implications but also responsive to the specific needs articulated by family caregivers. Additionally, the research acknowledges and respects situations where technology may not be desired by the target group.

# 4.2 Methodological Framework for the Workshop

The methodological framework for the present study is grounded in qualitative research principles, specifically employing the Design Thinking approach to facilitate an in-depth understanding of user needs and collaborative solution development. This framework emphasizes the iterative nature of the design process, allowing for continuous refinement of ideas based on participant feedback. [Aue21]

By leveraging structured focus groups, the research engages diverse stakeholders with an interdisciplinary background.

#### 4.2.1 Workshop Design

As part of the *Methodological Framework*, this section provides an overview of the workshop design by reflecting on key design decisions, such as location selection and the integration of specific design elements. Another aspect explored in this section is the justification for the Design Thinking phases utilized, as not all principles are applicable to this study.

#### Utilized Design Thinking Principles

The principles of *Design Thinking – empathize*, *define*, *ideate*, *prototype*, and *test –* provide a robust framework for understanding user needs and developing innovative solutions. The iterative nature of these phases is essential for refining solutions to ensure they effectively address user challenges.[Vas23]

Aligning with the research objectives, the workshop has been structured into four distinct phases: *empathize*, *define*, *ideate*, and *prototype*. The decision not to include the final phase, *test*, was deliberate, respecting the time constraints of participants who juggle professional and caregiving duties. This limitation necessitated a shorter workshop duration. Furthermore, the sensitive nature of the topics may prevent comprehensive exploration within the allotted time. Consequently, the testing phase is proposed for future work, allowing for thorough solution testing without overwhelming participants.

1. Empathize Phase:

This initial phase aims to build a deep understanding of the experiences, emotions, and challenges faced by participants, including both, family caregivers and experts. Initial discussions, warm-up questions, and the introduction of a persona for each focus group should foster an inspiring and respectful environment. The focus groups are intentionally kept small, with backup groups available to adapt and redistribute participants dynamically. This phase is critical, as it establishes foundational group dynamics and cohesion, directly influencing subsequent outcomes.[Vas23]

## 2. Define Phase:

During the define phase, participants are equipped with specific questions to brainstorm and identify a broad spectrum of associated problems. [Vas23] By clearly defining the problem space, both family caregivers and experts should create a shared understanding of their focus group's objectives. The **empathize** and **define** phases collectively constitute **Workshop Phase I**.

3. Ideate Phase:

Following the define phase, participants engage in structured brainstorming sessions to generate a wide array of potential solutions to the identified issues. This phase leverages the creative potential of participants and encourages the exploration of novel ideas. To facilitate ideation, participants are given specific tasks to address, utilizing techniques such as mind mapping and rapid sketching to stimulate creativity and encourage out-of-the-box thinking. Additional supporting materials will be provided for each focus group to enhance this process.[Vas23]

4. Prototype Phase:

In the final phase, participants refine their ideas from the ideation phase into low-fidelity prototypes. [Vas23] Collaborating in small groups, implementation strategies should be outlined by investigating potential impacts. This prototyping phase is crucial, as it transitions the workshop from abstract ideation to tangible solutions laying the ground the next phases of the study. The **ideate** and **prototype** phases will be integrated into **Workshop Phase II**.

# Workshop Setting

The workshop setting was designed according to the principles of collaboration, inclusion, creativity, and openness. To effectively implement these principles, several measures were taken to establish an optimal environment for participants.[Vas23][Aue21][SV22]

In this regard, the selection of the venue was pivotal. The chosen location was determined by predefined criteria that promote an atmosphere conducive to collaboration and inclusion.

To meet these requirements, the workshop was hosted at the same location as the attended  $Caf\acute{e}$  Zeitreise – a peer support group for PwD and their caregivers –, situated within the Kulturverein "das Hufnagl" in the 21st district of Vienna<sup>1</sup>. A further criterion for this selection was the location's accessibility for study participants, particularly to support caregivers in minimizing travel time and maximizing their availability for the workshop. Additionally, the venue's spacious and well-lit rooms facilitated unrestricted and focused group work, thereby promoting effective co-design sessions, as presented in Appendix B.3.

To further enhance creativity and openness within the focus groups, a *design thinking* box was prepared, as illustrated in the figure below.

<sup>&</sup>lt;sup>1</sup>https://www.das-hufnagl.at



Figure 4.2: Design Thinking Boxes for the Focus Groups

The boxes contained various office supplies, including sticky notes, pens, highlighters, and other materials specifically chosen to stimulate creativity and ideation.

Lastly, to avoid any ambiguity, it is important to clarify that the organizer of the workshop is also the author of this study. Consequently, all references to the facilitator, organizer, or coordinator of the workshop should be interpreted as referring to the author.

# 4.2.2 Workshop Participant Selection

Participants were recruited using a purposive sampling strategy designed to capture a diverse array of the user population, thereby fostering an interdisciplinary environment. [Rob14] The selection criteria prioritized demographic and professional diversity, emphasizing their relevance to the study's objectives. This approach ensured that the focus groups were well-balanced, with each group comprising: at least one family caregiver and one domain expert; and a minimum of three focus groups overall.

# Workshop Inclusion Criteria

For the workshop, the participant selection criteria mirrored those employed in the interviews to maintain consistency throughout the entire study.

- Inclusion Criteria:
  - **Family Caregivers:** Individuals, providing regular care for a family member with dementia, maintaining a familiar or defined relationship.
  - **Experts:** Professionals whose work is related to family caregivers or the caregiving landscape in Austria.
  - Health Condition of Care Recipient: Limited to PwD.
  - Residence: Both the caregiver and the care recipient resided in Austria.

Interview participation was not required for eligibility to collaborate in the workshop.

#### Workshop Recruitment Process

The recruitment of participants employed a multifaceted strategy that effectively leveraged both, personal and expanded secondary networks. Direct outreach efforts replicated those, utilized in previous phases, encompassing emails, phone calls, and personal visits. In addition, social media platforms such as LinkedIn facilitated connections with professionals in the caregiving field.

To further enhance outreach, established relationships with relevant organizations and stakeholders enabled the distribution of workshop recruitment materials, as the official workshop invitation, within their caregiving networks. The workshop invitation is in *Appendix B.1: Official Workshop Invitation with Agenda* included, and its ethical appropriateness has been validated by the ethical mentor of the study.

Additionally, the three, previously presented, peer support gatherings served as vital opportunities to recruit further family caregivers and domain experts, ensuring a diverse and representative participant pool for the workshop.

# 4.2.3 Workshop Data Collection and Analysis

Evaluating the effectiveness of the workshop necessitates a well-structured approach to data collection and analysis. This section delineates the systematic methodologies employed to gather data from participants and the analytical frameworks utilized to extract meaningful insights from the collected data.

## Workshop Data Collection

Given that the proposed workshop was designed to encourage dynamic exchanges among interdisciplinary focus groups, the selection of data collection methods was strategic to preserve the beneficial characteristics of Design Thinking in this setting. By leveraging the features of a non-laboratory environment, the workshop fostered a natural co-design atmosphere.

To capture the outcomes of the workshop, the following methods were employed:

- Personal Observations: Throughout the focus group sessions, the facilitator engaged in systematic observations of group dynamics. This methodological approach allowed for the identification of interaction patterns, levels of participant engagement, and the emergence of phenomena such as groupthink or conflict. [Aue21] [Par16] Observational data were documented using structured notes, capturing both verbal and non-verbal cues that are essential for contextualizing the qualitative data collected during discussions. [Par16]
- **Participant Feedback:** Structured feedback was solicited from participants during and at the conclusion of each focus group discussion by the workshop organizer. This feedback consisted of qualitative responses concerning their experiences, perceived value of the discussions, and suggestions for future workshops.[Sed16]

- **Tangible Outcomes:** Each focus group was tasked with generating specific outcomes, such as recommendations or strategies pertinent to their discussion topics. These outcomes were documented by participants using sticky notes and flip charts, providing material for subsequent analysis. They served as measurable indicators of the workshop's success and offered avenues for further exploration of the technical applicability of the concepts discussed.
- Audio Recordings: Final presentations were audio-recorded to facilitate comprehensive analysis. These recordings enabled a detailed examination of participant contributions, enriching the overall data set. Transcriptions of the recordings provided a textual foundation for further analysis, ensuring that all relevant points were captured, including those that may have been overlooked during real-time observation.

Thereby, data for this study were collected through a multi-faceted approach, integrating various methodologies to ensure a comprehensive understanding of participants' experiences and tangible outcomes.

#### Workshop Data Analysis

The analysis of the collected data was conducted using a structured and systematic approach to ensure rigor and validity:

- **Thematic Analysis:** A thematic analysis was conducted on the observations, feedback, and recorded discussions from the final presentations. This process involved several stages: initial familiarization with the data, identification of specific themes, and their subsequent categorization. The identified themes were analyzed in relation to the workshop objectives.[Bra12]
- Qualitative Analysis and Evaluation of Tangible Outcomes: The tangible outcomes generated by each focus group, in conjunction with the feedback obtained, were subjected to qualitative analysis. This analysis facilitated deeper insights into participants' experiences and their perceptions of the effectiveness of the focus group discussions. The resultant insights will inform the subsequent chapter, where the most technically relevant and mature solution will be further investigated.

Through the integration of these data collection and analysis methodologies, a rich and nuanced understanding of participants' perspectives was developed. The insights garnered from this study, will not only validate the effectiveness of the Design Thinking workshop within the caregiving domain, but will also confirm the efficacy of the implemented focus group settings, the incorporation of personas, and participant engagement in collaborative settings.

68

#### Limitations in Workshop Data Collection and Analysis

Despite the data collection methods employed, it is important to acknowledge that the design of the workshop, which involved multiple concurrent focus groups, may have resulted in some critical discussions not being fully captured. The facilitator recognized the limitations inherent in not being able to monitor all sessions simultaneously, meaning that some discussions that could have provided valuable insights may have gone unrecorded, potentially constraining the comprehensiveness of the findings. This consideration has been factored into the analytical process. Future workshops may consider alternative designs to address this issue, such as employing a larger observation team to capture a broader array of interactions.

# 4.3 Workshop Structure and Execution

The methodological approach for the Design Thinking Workshop was grounded in qualitative research principles, with a strong emphasis on participatory design.[Lor23] By utilizing focus groups as the primary method for data collection, the workshop facilitated an in-depth exploration of user requirements and perspectives. This approach aligns well with the principles of Design Thinking, where user-centered insights are paramount for developing effective solutions. Thereby, the incorporation of personas aims to enrich focus group discussions, fostering deeper engagement, while shifting the focus away from personal intentions.[Lor23][SV22][Vas23]

#### 4.3.1 Workshop Agenda

Designed as a half-day workshop, the event comprised two main phases: Workshop Phase I and Workshop Phase II. A detailed structure of the agenda can be found in Appendix B.1: Official Workshop Invitation with Agenda.

In **Phase I**, the focus was on establishing a solid foundation, shaping the discussion topics, and facilitating initial conversations that incorporated personal experiences related to caregiving. This phase aimed to create a shared understanding among participants and ensure that diverse perspectives were represented.

While **Phase II** provided participants with the opportunity to engage in prototyping, where they could creatively propose innovative solutions to the identified problems. This phase was designed to encourage collaboration and the exploration of actionable ideas.

An additional aspect of the agenda was designed to accommodate participants' personal obligations, allowing them to leave the event as needed. To facilitate this, each phase of the workshop was structured to ensure a clear outcome, enabling participants to engage meaningfully even if they had to depart early.

Furthermore, promoting group cohesion and a positive atmosphere, networking opportunities were integrated, as a communal breakfast and a lunch break with catering. The final part of the DT Workshop involved the final presentations, accompanied by informal coffee talks to support exchanges among participants and reflect on findings.

#### 4.3.2 Focus Group Development

The decision to utilize focus groups stemmed from the aim of creating a supportive, open environment, where participants could share their experiences and collaboratively generate ideas. Smaller group settings were especially beneficial for discussing sensitive topics, like dementia care for a family member. Each focus group was organized around a specific theme, addressing key aspects of caregiving, including legal and organizational hurdles, mental well-being, and practical issues such as managing daily routines – detailed in *Appendix B.4*. This thematic focus facilitated targeted discussions and more meaningful insights, covering all relevant aspects gained through the interviews.

Based on the anticipated number of participants, five focus groups were established, as presented in the figure below. Icons have been utilized via Shutterstock<sup>2</sup>.



Figure 4.3: Developed Focus Groups including a Backup Group Source: Created by Author

In addition, the figure provides an overview of each focus group's primary tasks and the planned distribution of participants, thereby, following focus groups have been defined:

- Focus Group 1: Starter Kit for Family Caregivers
- Focus Group 2: Digital Calendar & Checklist
- Focus Group 3: Care Allowance Guide & Documentation
- Focus Group 4: Networking & Knowledge Transfer
- Focus Group 5: Backup Group: Mental Well-Being

<sup>2</sup>https://www.shutterstock.com/

For qualitative outcomes, a minimum requirement was defined for each focus group to consist of at least three participants, ensuring the inclusion of one family caregiver and one domain expert. This composition was designed to facilitate heterogeneous exchanges, thereby enriching the discussions with diverse perspectives and experiences.

Hence, participants were assigned to the focus groups prior to the workshop based on their experiences and personal motivation, expertise, and the current challenges they faced. Such an approach boosted conversations in which experts could meaningfully contribute and directly reflect on user requirements and feedback.

#### Persona Development

The introduction of personas serves as a creative tool that sensitizes participants to the complexities of caregiving, particularly in the context of dementia. By empathizing with the assigned persona, participants are able to gain deeper insights into the problem space, prompting them to consider alternative viewpoints and engage in comprehensive discussions. This process fosters a collaborative environment that enhances the generation of innovative solutions.

Furthermore, the strategic implementation of personas is instrumental in upholding objectivity and reducing biases that may influence participants' judgments. By reflecting on their own experiences alongside those of the assigned personas, participants are guided to step beyond their individual perspectives and emotional drivers. This connection not only enriches the dialogue but also ensures that discussions remain focused on broader caregiving challenges rather than on personal viewpoints.

An overview of the personas is presented in the figure below, while comprehensive descriptions for each focus group can be found in *Appendix B.4: Comprehensive Workshop Materials by Focus Group*, introduced at the beginning of each section.

Thereby, the personas (e.g., Anna, David, Lisa, Mark, and Sarah) are developed based on fictive scenarios that are inspired by real-world caregiving situations. They reflect a diverse array of caregiving roles, encompassing varying stages of dementia of the care recipient, different levels of caregiving responsibility, and distinct personal circumstances. This careful consideration in persona development ensures that focus group discussions are pertinent to the real-life challenges experienced by participants.

# Focus Group 1 - Starter Kit for Family Caregivers

The primary objective of this focus group was to develop a structured starter kit for family caregivers in the early stages of their caregiving journey. Thereby, the focus was on addressing the legal and administrative challenges associated with adult guardianship, ensuring that caregivers have access to clear, actionable information. By utilizing Anna's persona, the group sought to identify critical pain points and gaps in the current support system, while proposing practical tools to streamline the caregiving process.

A detailed description of Focus Group 1 can be found in Appendix B.4.1.

Personas o	f the Focus G	roups		
		2		
Anna	David	Lisa	Mark	(Backup Persona) Sarah
Age: 35	Age: 75	Age: 55	Age: 40	Age: 60
Relationship: Arma has recently received the medical diagnosis of her father's dementia. She is the primary family categories and is considering taking on the responsibility for her father's care and legal affairs in an official capacity but is unsure about the ethical correctness and the appropriate way to handle it.	Relationship: David is the sponse and cares for his wife, who has been diagnosed with demential. He wants to make the most of his time to provide the best possible care for his wife while also managing his own responsibilities.	Relationship: Lisa har recently found out that her mother has early-stage dementia. She is seeking information on how to obtain financial support and needs guidance on the steps in the application process for care benefits.	Relationship: Mark has been caring for his father, who suffers from dementia, for two years. During this time, he has recognized the importance of support and information exchange. To feel less overwhelmed, he wants to connect with other family caregivers.	Relationship: Sarah has been caring for her husband, who suffers from advanced dementia, for over six years. She is experiencing, burrout as a yrinary caregiver and is seeking emotional support as well as strategies to maintain her mental well-being.
Carrent Situation: Her father's dementia is in the early stages, so legal frameworks are still applicable.	Current Situation: His wife's dementia has progressed to a point where she requires round-the-clock care. She has been classified a care level 3, which makes David eligible for care benefits.	Current Situation: Lias's mother has not yet been classified for care benefits, but Lias is exploring her options as her mother's condition worsens. A diagnosis of the disease is already in place.	Current Situation: Mark's father has been classified as care level 4, and Mark is looking for additional resources to support him in his caregoing role. Since he often feels uncertain about how to best approach his father and is generally unsure about his father and is generally unsure about has precise genuine feedback from upperclate genuine feedback from	Current Situation: Although Sarah receives professional support in caregoring, the emotional burden is becoming increasingly severe. Despite the possibility of obtaining ne placing her husband in a nursing home due to concerne for his well-being and their close bond.
Informatics		22		

Figure 4.4: Overview of Personas Developed for Focus Groups 1 to 5 Source: Created by Author

#### Persona Characteristics:

The persona for this group, Anna, a 35-year-old primary caregiver for her father with early-stage dementia, reflects the challenges of newly assumed caregiving responsibilities, particularly regarding legal and administrative aspects like adult guardianship. The intention of the persona was to surface the ethical dilemmas caregivers face when balancing personal emotional involvement with legal responsibilities.

#### Workshop Phase I:

Participants were asked to reflect on their experiences and identify key challenges encountered early in their caregiving roles, focusing on resources that could have helped manage legal and administrative burdens. By brainstorming needs and available support systems, participants were asked, in addition, on the limitations in accessing legal guidance and other essential resources.

#### Workshop Phase II:

As part of the second phase, participants were tasked with solution development, to collaboratively design components for a comprehensive starter kit. The task involved creating clear, user-friendly guides and visual tools, such as checklists, aimed at simplifying legal procedures. Additionally, participants were asked to explore how existing resources could be improved or expanded, suggesting the inclusion of educational materials like workshops and training sessions to better equip caregivers with legal and caregiving knowledge. The aim was to produce materials that not only covered legal aspects, but also offered practical, actionable support for day-to-day caregiving tasks.

72

#### Focus Group 2 - Digital Calendar & Checklist

In the present focus group, the primary aim was to develop a digital calendar and checklist tool tailored to the specific organizational needs of family caregivers. By focusing on improving coordination between caregivers, healthcare professionals, and other stakeholders, the group sought to create a tool that would help manage caregiving responsibilities alongside personal commitments more effectively.

For Focus Group 2, a comprehensive overview of the materials can be obtained in Appendix B.4.2.

#### **Persona Characteristics:**

David, the persona for this group, is a 75-year-old man caring for his wife, who has been diagnosed with advanced dementia and now requires constant care. His objective is to balance his caregiving duties with his personal responsibilities, ensuring his wife receives the best possible care. This persona was utilized to highlight the real-life organizational challenges faced by caregivers in similar situations.

#### Workshop Phase I:

In this phase, participants were invited to reflect on the major organizational difficulties they might encounter when managing caregiving tasks. They were asked to brainstorm specific challenges, such as identifying inefficiencies in current scheduling tools and recognizing difficulties in coordinating care among multiple parties. Additionally, participants were encouraged to share insights on how they might utilize digital tools like calendars and to-do lists, with the goal of identifying areas where these tools could be enhanced to better support their caregiving roles and facilitate smoother communication.

#### Workshop Phase II:

During the second phase, participants were invited to collaborate on designing a weekly calendar that focuses on David's caregiving duties. They were tasked with incorporating relevant features, such as scheduling medical appointments, family visits, and professional caregiving services. The exercise aimed to explore potential benefits of features like shared calendar access for multiple stakeholder, color-coded task prioritization, and the integration of daily to-do lists and checklists. Hence, to develop a tool that optimizes caregiving logistics while improving communication and collaboration among other care providers.

#### Focus Group 3 - Care Allowance Guide & Documentation

In Focus Group 3, the primary objective was to identify the essential needs and motivations of family caregivers navigating the care allowance system. By concentrating on the challenges associated with the application process for financial support, the group was tasked to develop actionable strategies that would facilitate access to necessary resources.

A comprehensive overview of the materials for Focus Group 3 can be obtained in Appendix B.4.3.

#### 4. Design Thinking Workshop

#### **Persona Characteristics:**

Lisa, the persona represented in this group, is a 55-year-old woman who has recently discovered that her mother has early-stage dementia. In her pursuit of guidance on securing financial assistance, Lisa represents individuals in similar circumstances who are navigating their options as they cope with the progressive decline of a loved one's condition. Her persona highlights the urgency for clear, accessible information regarding the care allowance application process.

#### Workshop Phase I:

Participants were invited to reflect on the primary obstacles they may have faced while navigating the care allowance system in Austria. They were tasked with identifying specific challenges, such as the complexities within the application process and the accessibility of information regarding eligibility. Furthermore, participants were encouraged to brainstorm ways to enhance the clarity and availability of resources related to the care allowance, ensuring that future caregivers can easily find and understand the necessary steps involved.

#### Workshop Phase II:

At this stage of the workshop, participants were invited to collaboratively create a step-by-step guide to assist Lisa in applying for care allowance. This guide was intended to outline critical steps, including the completion of application forms and an overview of eligibility criteria. By discussing potential barriers and gaps in current support services, the group was tasked to develop a comprehensive guide that could empower caregivers and facilitate a smoother application process.

#### Focus Group 4 - Networking & Knowledge Transfer

The present focus group was designed to identify the core needs and motivations of family caregivers navigating the complexities of dementia care. Central to this initiative was the establishment of a network and mechanisms for knowledge transfer among caregivers, aimed at promoting the exchange of experiences, tips, and resources while providing mutual support. The planned discussions were intended to develop strategies that may enhance access to valuable resources and strengthen connections among caregivers, ultimately fostering a supportive community that addresses their shared challenges.

A comprehensive overview of the materials can be found in *Appendix B.4.4* for Focus Group 4.

#### **Persona Characteristics:**

Mark, the persona represented in this group, is a 40-year-old man who has been caring for his father with dementia for the past two years. Through his experience, Mark has recognized the importance of support and knowledge exchange. He seeks to connect with other caregivers to gain insights that can alleviate his feelings of being overwhelmed. His situation underscores the necessity for accessible networks and resources that facilitate peer support.

#### Workshop Phase I:

In Workshop Phase I., participants were invited to reflect on the primary challenges

they encounter when accessing reliable information and support related to dementia care. They were tasked with identifying specific barriers that complicate this access, such as the availability of resources and the clarity of information. Additionally, participants were asked to exchange on essential topics that should be addressed in a peer support network or knowledge database, compiling their insights to inform future initiatives.

Workshop Phase II: In the second phase of the workshop, participants were tasked with exploring ways to connect caregivers like Mark with existing networks and resources. The objective was to create a comprehensive map outlining available support options, including hotlines, community groups, and online forums. This map was intended to serve as a practical guide for Mark and others, facilitating their navigation of the support services tailored to their needs. Additionally, participants were to identify gaps in current offerings, aiming to propose improvements that would enhance networking opportunities and facilitate knowledge sharing among caregivers.

#### Focus Group 5 - Backup Group: Mental Well-Being

The primary aim of this group was to identify the critical needs and motivations of family caregivers concerning their mental well-being. By fostering social connections and promoting self-care strategies, the objective was to mitigate the emotional challenges that caregivers often face.

Appendix B.4.5 contains a thorough overview of the materials related to Focus Group 5.

**Persona Characteristics:** The present focus group featured Sarah, a 60-year-old family caregiver who has been supporting her husband, who suffers from advanced dementia, for over six years. Currently grappling with significant burnout, Sarah seeks emotional support and effective strategies to maintain her mental well-being. Her circumstances underscore the urgent need for resources specifically tailored to address the psychological challenges encountered by caregivers.

Workshop Phase I: Participants were expected to engage in discussions surrounding the key obstacles caregivers confront regarding their mental health. The primary objective was to uncover how these difficulties impact their ability to provide balanced and effective care. They were tasked with evaluating existing mental health resources and support services, analyzing their effectiveness, and sharing personal coping strategies that have proven beneficial. This exploration aimed to generate actionable insights for the development of future support initiatives.

Workshop Phase II: The subsequent phase was structured to guide participants in compiling a comprehensive resource overview tailored to assist caregivers like Sarah in improving their mental wellness. This included cataloging available counseling and therapy options, assessing their accessibility, and determining their effectiveness. Additionally, participants received the task to "Self-Care Resource Kits" that encompass a variety of mental health support techniques, as well as identify communities and support networks that facilitate caregiver interactions. Furthermore, the group was asked to establish a mentoring platform that pairs caregivers with both professional and peer mentors to enhance emotional support and resilience.

# 4.4 Workshop Findings and Discussion

Based on the total number of workshop attendees and observed group dynamics, four out of the five previously presented focus groups were utilized:

- Focus Group 1: Starter Kit for Family Caregivers
- Focus Group 2: Digital Calendar & Checklist
- Focus Group 3: Care Allowance Guide & Documentation
- Focus Group 4: Networking & Knowledge Transfer

Consequently, the backup, Focus Group 5, with its primary objective of addressing the mental well-being of family caregivers, was not included. Nevertheless, the study acknowledges the critical importance of the topic, and suggests that it be explored in a dedicated future study, focusing solely on this intersection.

Additional documentation, including photographs of the workshop outcomes, is available in Appendix B.4: Comprehensive Workshop Materials by Focus Group.

#### Workshop Participant Numbers and Demographics

According to the actual numbers, a total of 12 active workshop participants were distributed across 4 distinct focus groups, comprising 8 females (F) and 4 males (M). Further participants in the workshop included the study mentor and two coordinators. The mentor ensured adherence to professional and ethical standards, while the coordinators took on distinct responsibilities – one managing catering logistics and the other, the author of this study, coordinating the overall workflow and workshop activities. This brought the total number of participants to 16, as detailed in *Table 4.1*..

Family caregivers in this study comprised both, working professionals and retirees, who provide care to family members with dementia. Their relationships with the care recipients varied, encompassing marriage or parent-child dynamics, among other. The caregiving experiences of participants also differed significantly, in terms of duration and intensity, reflecting the complexities of their roles. Additionally, the types of care provided ranged from occasional organizational tasks to more intensive daily caregiving activities, such as administering medications or preparing meals.

All participants' backgrounds, including their professional experiences and caregiving relationships, were carefully assessed by the author based on prior exchanges. This comprehensive understanding fostered a significant level of trust in their workshop participation, as evidenced by their direct feedback. Moreover, it enabled a more strategic distribution of individuals within the focus groups. Due to privacy considerations, the present study will not disclose additional personally identifiable information regarding the demographic characteristics of the participants.

Workshop Teams	Participant Category	Function	
Focus Group 1: Starter Kit for Family Caregivers	Family Caregiver 1 (F) Expert 1 (F) Expert 2 (F)	Primary Caregiver Dementia Care Specialist Psychologist	
Focus Group 2: Digital Calendar ど Checklist	Family Caregiver 2 (F) Family Caregiver 3 (M) Expert 3 (F) Expert 4 (M)	Primary Caregiver Primary Caregiver Technology Developer Healthcare Consultant	
Focus Group 3: Care Allowance Guide & Documentation	Family Caregiver 4 (M) Family Caregiver 5 (M) Expert 5 (F)	Primary Caregiver Primary Caregiver Physical Therapist	
Focus Group 4: Networking ど Knowledge Transfer	Family Caregiver 6 (F) Expert 6 (F) Expert 7 (F)	Primary Caregiver Social Worker Community Care Coordinator	
Total FC Participants:	12 Participants		
		6 Family Caregivers 7 Experts	
Workshop Mentoring	Thesis Mentor 1 (F)	Research Mentoring	
Organisation Team	Coordinator 1 (M) Coordinator 2 (F)	Catering Coordinator Event Coordinator Author of the Present Work	
<b>Total Participants:</b>	16 Participants		
		<ul><li>7 Experts</li><li>6 Family Caregivers</li><li>1 Mentor</li><li>2 Coordinators</li></ul>	

Table 4.1: Focus Groups and Roles: Participant Composition and Expertise

In terms of expert involvement, a diverse array of stakeholders contributed to the workshop, offering invaluable guidance to family caregivers as they navigated the assigned tasks. This participation significantly elevated the quality of both the workshop and the co-design process. Moreover, the presence of these experts facilitated direct feedback and exchanges regarding specific challenges and inquiries faced by participants. Consequently, the workshop outcomes already incorporate multiple feedback loops, which are anticipated to enrich future validation processes and inform the development of a more refined strategy.

Thus, expert participants included representatives from the *Caritas Pflege*, *FSW*, *Interessengemeinschaft pflegender Angehöriger*, *Sozialministerium*, *TU Wien*, and *Young Carers App*. The professional roles represented comprised certified former caregivers, healthcare professionals, project workers focused on family caregivers, and computer scientists with domain expertise in assistive technologies.

Subsequent sections will detail the discussions highlighted by workshop participants and provide an analysis of the tangible results. All citations within this section will exclusively pertain to statements made by members of the respective focus groups during their final presentations.

#### 4.4.1 Reflection on Focus Group 1 - Starter Kit for Family Caregivers

The discussions and outcomes of Focus Group 1 emphasize the key challenges that family caregivers, such as Anna, face when managing early-stage dementia of a family member. The problem areas identified in the workshop, underscore the importance of providing timely and targeted information to caregivers, enabling them to fulfill their new role effectively. As a primary pain point, it was noted that while many resources already exist, their accessibility and consolidation into a single, user-friendly platform are seen as significant barriers: "Wir sind der Meinung, dass die Angebote ja vorhanden sind, es ist ja nicht, dass irgendwas fehlt, das Einzige, was immer das Problem ist, ist, dass individuell das Passende zu finden. ... Das Problem liegt also in der Erreichbarkeit und in der Übersichtlichkeit dessen, was eben zur Verfügung steht." according to a participant in Focus Group 1.

During the group's final presentation, a further major insight represented that access to information often does not occur early enough or is not available in a compact form. One suggestion was to provide information in the form of a "One-Stop-Shop" to ensure that affected individuals receive the necessary resources directly, without getting lost in a maze of information: "Im Sinne eines One-Stop-Shops, also dass man dort alle Infos kriegt, die man benötigt.". Nevertheless, as noted on the group's final flipchart, presented in the figure below, the website pflege.gv.at, operated by the Austrian government, serves as a fundamental and reliable source.

On a further note, the general social sensitization of the matter was highlighted and referred to as crucial. According to recommendations by the focus group, infoscreens could be utilized here: *"Ein Punkt, um die Erreichbarkeit zu erleichtern, wäre sicher* 

STARTPAKET für ANNA Erreichbarkeit: - direkt nach Diagnose durch Arzt/Arztin - multiprofessionelles Team von Vorteil (One-Sip) gesellschaftliche Jensibilisierung Annas Arbeitgeber Hindernisse Medien, Infoscreen, Medizin/Apotheken Kosten, Zugangsschwelten Themen -rechtlich/administrativ -> Infos + Unterstützung bei Antrag + Abwicklung Erwachsenenvertretung, Vorsorgevollmecht, Patientenverfügung, Kontozugang Pflegekarenz, Jozielversicherung, Pflegegeld -> Unterstützungsmöglicken durch professionelle Dienste = D landerspezifische Unterschiede P pflege.gv.at. ? - psychosoziale Gesundheit + Unterstützung -> Wissen zur Erkrankung -> Wissen zur Möglichkeit und über die Notwendigkeit von Eutlastung → psychosoziale Baglaitung → Elbsthilfegruppen Angebole sind vorhanden Problem liegt bei Erreichbarkeit und in der Übersichtlichkeit Rahmen bedingungen : 0 Beratung, nachgehend + niederschwellig, regionale Informationen kontinuierliche Begleitungursus

Figure 4.5: Design Thinking Workshop Outcome of Focus Group 1 - Workshop Phase II.

die allgemeine gesellschaftliche Sensibilisierung. ... Da hätten wir eben gemeint, Info-Screen, beim Mediziner die Info-Screen oder in der Straßenbahn, in der U-Bahn oder in Apotheken."

Another crucial aspect pertained to the legal and administrative challenges. Focus Group 1 emphasized the need for caregivers to be informed about legal measures, such as the *health care proxy [Vorsorgevollmacht]* or *adult representation [Erwachsenvertretung]*. In this context, the health care proxy was considered a priority, as it offers a more suitable solution for people in the early stages of dementia and their family caregivers, where affected individuals are still capable of making their own decisions. This legal framework is a precautionary power of attorney that only becomes effective if the person is no longer capable of making own decisions on certain things. While adult guardianship becomes necessary only in later phases and is also associated with more complex procedures due to its significant legal power.[oes24] Hence, information on such a precautionary step has been identified by the focus group as helpful, as the following statement supports: "Das Niederschwelligste, um alles zu regeln, nämlich für mich selber zu regeln, ist eben die Vorsorgevollmacht."

In addition to legal guidance, the psychosocial aspect was highlighted. It was emphasized that caregivers' mental health is often neglected. The group identified support groups as a valuable resource for emotional support and exchange: "Was die psychosoziale Gesundheit und Unterstützung angeht, ist es wichtig, ... welche Möglichkeiten der psychosozialen, nicht nur Beratung, sondern auch Begleitung gibt es, und da sehen wir besonders die Selbsthilfegruppen als besonders wichtig, weil man sich dort eben austauschen kann."

These insights from the discussion highlight that a structured starter kit for caregivers, as developed in the workshop, should include both legal and psychosocial support. At the same time, access to this information must be simplified to enhance usability and user satisfaction.

#### Assessing Technical Affinity of Discussion Points in Focus Group 1

The pain points mentioned by Focus Group 1 reveal significant potential for addressing caregivers' challenges through technical solutions. One of the core issues identified was the difficulty caregivers face in accessing timely and relevant information. This problem could be mitigated through the development of a comprehensive, centralized, and layered information platform, such as an app or website, where caregivers can access relevant information at different levels of detail. This would allow caregivers to quickly find the most relevant information, while also offering the opportunity to explore more specific topics in greater depth. A hierarchical structure would enable users to start with general overviews and progressively access more specialized content as needed.

From a technical perspective, this type of platform could be enhanced through AIpowered personalized content, based on the user's caregiving stage and specific needs. By tracking user interactions and preferences, the platform could present information in a more targeted way, reducing the overwhelm caregivers often experience when faced with vast amounts of information. In addition, reminder and notification functions for new regulations or supporting structures could enhance caregivers' situations: "... was immer das Problem ist, ist, dass individuell das Passende zu finden.."

Furthermore, a well-designed platform could include integration with other digital services, such as online support groups or chatbots, providing caregivers with not only knowledge transfer but also emotional support. An inspiration and success story in this regard could be the app, Headspace, which has developed distinct practices relying on meditation for balancing mental well-being. [Cal24] This would address the psychosocial component discussed in the workshop, ensuring that caregivers have access to a comprehensive care system.

Additionally, incorporating legal tools, such as digital forms for health care proxy or step-by-step guidance for applying for care allowance, would further alleviate the administrative burden highlighted in the group discussions: "Was wir brauchen, sind Infos zur Unterstützung, wie kriege ich einen Antrag... Vorsorgevollmacht...".

Another important aspect centered around the need to sensitize society to dementia in general and the role of family caregivers. As one participant suggested, the utilization of infoscreens could be an effective tool for raising awareness and sensitizing the public to the needs and importance of family caregivers. Thereby, developing short videos for this purpose could reach a wide audience.

In conclusion, the identified problem areas in Focus Group 1, offer numerous opportunities for technological innovation. A user-friendly, layered digital platform, integrated with personalized content and legal tools, could significantly enhance the caregiving experience by addressing both, informational and emotional needs in a structured, accessible format.

# 4.4.2 Reflection on Focus Group 2 - Digital Calendar & Checklist

In the second focus group, the primary objective centered on the design of a digital calendar and checklist to efficiently manage caregiving tasks and other organizational matters. This focus group was the largest in terms of team size, which may contribute to the depth and maturity of the outcomes, as illustrated in the figure below. Comprising four participants, the group effectively tackled key issues related to enhancing both, self-management and the management of the care recipient's needs.

Thereby, the group identified three main challenges that caregivers face: documentation, organization, and health management, along with the essential aspect of self-care.



Figure 4.6: Design Thinking Workshop Outcome of Focus Group 2 - Workshop Phase II.

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82

Key Challenges Identified:

- **Documentation**: A significant issue noted by the group was the uncertainty around what needs to be documented in caregiving. Caregivers often realize too late what information is necessary for effective care. Suggestions included creating checklists or structured guides to clarify what should be documented, enabling caregivers to track vital aspects of their loved one's care effectively. As highlighted in the discussion, "Da ist es im Vorhinein oft unklar, was man eigentlich dokumentieren muss. Und man kommt erst zu einem Punkt drauf, wo es eigentlich eher schon spät ist."
- Organization: The complexity of organizing care for another person was highlighted as a major challenge. Caregivers are not only tasked with physical care but also the logistical management of daily routines. The term "Auftröseln" (breaking down tasks) emerged as critical, emphasizing the need for caregivers to deconstruct daily activities into manageable components. One participant stated, "Man managt nämlich das Leben einer anderen Person mit. Das ist keine Pflegetätigkeit, sondern eine Organisationstätigkeit, für die man einen Terminplan braucht und die Aktivitäten auftröseln muss."
- Health Management and Self-Care: The responsibility for the health of the person being cared for weighs heavily on caregivers. They must motivate and engage their loved ones while also ensuring their own well-being. Focus Group 2 stressed the importance of self-care, urging caregivers to prioritize their own health to prevent burnout. It was emphasized that "man muss auch auf sich selbst schauen und nicht nur auf die zu pflegende Person."

To address these challenges, the focus group proposed several innovative tools and strategies.

# **Proposed Solutions:**

- Digital Tools: A digital platform for a shared calendar and to-do list was deemed essential for enhancing organization. This platform would allow caregivers to manage their responsibilities and communicate with family members involved in the care. Participants suggested, "Es wäre fein, wenn sich das ersetzen lassen würde, oder ergänzen lassen würde, um eine personenbezogene Plattform mit Infos und Status zu der zu pflegenden Person."
- Interactive Features: Incorporating interactive elements into the caregiving tools—such as reminders for significant dates, visual cues for time of day, and features that encourage engagement with the care recipient—was discussed. A participant noted, "Man könnte auch Interaktionen nutzen. Man könnte zum Beispiel spezielle Abschnitte machen, wo erinnert wird an einen Hochzeitstag oder an den Geburtstag eines älteren Kindes."

#### DESIGN THINKING WORKSHOP 4.

- Self-Reflection Journals: The group recognized the value of a journaling feature within the caregiving tool, allowing caregivers to document their experiences and emotions. This would serve as both, a record of changes in the care recipient's condition and a means for caregivers to process their feelings and experiences. One member remarked, "Andererseits aber auch ein bisschen Platz ist für Selbstreflexion. Was ist an diesem Tag auch mit den Pflegenden passiert? Mit den pflegenden Angehörigen passiert? Was habe ich unter Umständen Nettes erlebt an diesem Tag oder Negatives erlebt? Weil es hat auch nicht jeder immer so seine Gesprächsbasis rundherum."
- **Emphasizing Community and Support:** The discussion also highlighted the importance of community support among caregivers. Participants suggested leveraging existing family networks, enabling caregivers to share responsibilities and check in on one another. Utilizing platforms like WhatsApp for family communication about the care recipient's status was recommended and the creation of an action plan, as one participant articulated: "Und dann gibt es noch, eine WhatsApp Familiengruppe. .../description of a scenario/ die Mama ist alleine daheim. Dann meldet sich irgendwer aus der Gruppe und sagt, passt, ich rufe in zwei Stunden bei ihr an und schau, wie es ihr geht. Damit verbunden auch ein eventueller Einsatzplan."

The reflections from Focus Group 2 reveal that caregiving for individuals with dementia is not merely a task but a complex interplay of documentation, organization, and health management, underpinned by the caregiver's need for self-care. The proposed solutions, particularly the development of a user-friendly digital platform for sharing information and managing care, hold significant promise for improving the caregiving experience. By addressing both the logistical and emotional aspects of caregiving, a digital calendar with various functionalities can empower caregivers, like David, to provide optimal care for their loved ones while maintaining their well-being.

#### Assessing Technical Affinity of Discussion Points in Focus Group 2

The technical affinity of the second group's discussion on the digital calendar and checklist highlights the participants' strong preference for digital solutions in caregiving contexts. This preference stems from the flexibility and adaptability that digital tools offer, as emphasized by the group's consensus: "Wir wollen das Digital haben. Warum? Weil es viel flexibler ist.". This indicates a clear recognition that digital formats can provide caregivers with the necessary tools to efficiently manage their responsibilities and adapt to the evolving needs of the care recipient.

#### **Documentation Requirements**

One of the main challenges identified was the ambiguity surrounding the documentation that caregivers need to perform. To address this, implementing structured documentation templates within the digital tool could greatly assist caregivers in systematically recording vital information. These templates would allow users to input data in pre-defined categories relevant to caregiving, such as daily observations, medication logs, and health

84

changes. This standardization could reduce variability and enhance the completeness of records.

Moreover, contextual reminders and alerts could be integrated into the tool to prompt caregivers to document specific information at appropriate times. Such reminders would be especially helpful when linked to predefined routines, ensuring that timely and relevant updates are made.

# **Organizational Complexities**

The group also highlighted the complexities involved in organizing both personal tasks and those of the care recipient. To combat this, a dynamic visual scheduling interface could be developed, using visual cues like color coding and icons to facilitate easier navigation and comprehension of daily tasks. This approach would not only help caregivers recognize patterns in caregiving activities but also allow them to quickly adjust their plans in response to shifting priorities.

Additionally, the concept of "Auftröseln," or breaking down complex tasks into manageable sub-tasks, could be effectively implemented through an interactive task management feature. Caregivers could input overarching tasks and receive suggestions for subdividing them into actionable steps, enhancing clarity and focus in their planning.

# Health Management Responsibilities

The responsibility of managing the health of the care recipient, along with the caregiver's own well-being, is another critical aspect. Integrating health monitoring tools, medication reminders, and doctor's appointment scheduling features within a digital calendar could streamline the tracking of health metrics and simplify care coordination.

To further support caregivers, the tool could include self-care alerts that remind them to schedule personal appointments or dedicate time for leisure activities. This functionality is vital in ensuring that caregivers do not neglect their own health amid the demands of caregiving.

# Customization and Collaborative Features

Another important insight from the group was the need for personalization and collaborative functionalities within the digital tool. Providing user-centric customization options would allow caregivers to tailor the interface according to their preferences, enhancing user engagement and facilitating easier navigation.

Implementing a role-based access control system would also be essential for maintaining privacy and security. This feature would allow different family members to interact with the calendar according to their designated roles, ensuring sensitive information remains protected while fostering collaborative caregiving.

# AI-Driven Enhancements and Interactive Features

The integration of AI offers exciting possibilities to enhance the digital tool's functionality. For instance, predictive analytics could analyze user behavior and suggest optimal task scheduling or documentation reminders based on past interactions.[VK24] This personalized approach would make the tool more responsive to the caregiver's needs.

#### 4. Design Thinking Workshop

Additionally, interactive engagement mechanisms could facilitate emotional connections. Features that allow caregivers to set reminders for significant dates (like anniversaries and birthdays) or include personal images could foster a more supportive environment for both caregivers and care recipients. As one participant noted, "... wo erinnert wird an einen Hochzeitstag oder an den Geburtstag eines älteren Kindes. Und vielleicht ein Foto reingeben. Und vielleicht das auch als Interaktionsmöglichkeit nutzen und gleich ein Videocall aufzubauen für ein Enkelkind oder so.". Such interactions would improve user engagement and encourage positive emotional experiences.

#### Enhancing User Experience Through Design Principles

Finally, to ensure optimal usability of the digital calendar and checklist, a user-centered design approach is crucial. This would involve creating an intuitive user interface with clear icons, logical flow, and easily accessible help sections. Such thoughtful design would improve user-satisfaction for individuals with varying levels of technical proficiency.

Incorporating mechanisms for users to provide feedback on their experiences would facilitate continuous improvement of the tool. By allowing the tool to evolve in response to user needs and preferences, developers can ensure it remains relevant and effective.

The insights gathered from Focus Group 2 provide a robust foundation for designing a digital calendar and checklist tailored to the needs of caregivers. By addressing documentation challenges, enhancing organizational capabilities, and integrating health management features, the proposed digital tool can empower caregivers to better manage their responsibilities. Moreover, incorporating customization, role-based access, and AI-driven functionalities will not only improve the user experience but also foster a supportive caregiving environment.

# 4.4.3 Reflection on Focus Group 3 - Care Allowance Guide & Documentation

In Focus Group 3, the primary aim was to explore the essential needs and motivations of family caregivers navigating the care allowance system. The group concentrated on identifying the challenges that caregivers face, especially concerning the complex application process for financial support. Through reflective discussion, the participants aimed to develop actionable strategies that would enhance accessibility to necessary resources, thereby alleviating the administrative burdens on caregivers, as presented in the upcoming figure.

Family caregivers frequently encounter bureaucratic obstacles, and yet their emotional and physical workload often remains underappreciated. As one participant remarked, "Es ist nicht nur der Papierkram, der uns belastet, sondern auch das Gefühl, dass niemand uns unterstützt." This statement captures the dual challenge of navigating both a complex system and an overwhelming caregiving role.





An additional key theme that emerged in the discussions was the complexity of the care allowance documentation. Participants repeatedly expressed frustration with the unnecessarily convoluted nature of the application process, which often deterred them from fully engaging with the system. The group identified legal jargon, unclear eligibility criteria, and inconsistent instructions as key sources of confusion. These barriers not only delayed applications but also contributed to heightened anxiety among caregivers, who were unsure whether they had completed the forms correctly.

One caregiver highlighted this frustration by stating, "Es fühlt sich an, als ob man einen Abschluss in Bürokratie braucht, um diese Anträge zu verstehen." This sentiment resonated throughout the group, as many caregivers echoed the experience of feeling overwhelmed by the administrative burden. The complexity of the process often discouraged them from even attempting to apply, as the risk of submitting incomplete or incorrect forms seemed too great.

This problem reflects a broader systemic issue in social welfare administration, where intricate processes often alienate the very individuals they are meant to assist. As noted by one participant, "Man fühlt sich verloren im System, und wenn man versucht, Hilfe zu bekommen, bekommt man nur noch mehr Formulare." This reflects that even when assistance is attained, it frequently leads to additional bureaucratic steps rather than targeted solutions.

Participants frequently pointed out the lack of personal assistance or caseworkers who could help guide them through the process. The need for administrative support was apparent, with one caregiver stating, "Man hat das Gefühl, ganz allein gegen einen riesigen Berg aus Papier zu kämpfen."

Reflecting on these challenges, the group identified several actionable strategies to address the difficulties caregivers face. A key recommendation was the development of a simplified, user-friendly guide that clearly explains the application process. This guide would break down complex legal terms into plain language, provide step-by-step instructions, and include practical examples to make the process more accessible to all caregivers, particularly those with limited administrative experience. As one participant suggested, "Es wäre hilfreich, wenn man eine einfache Anleitung hätte, die einem genau sagt, was man tun muss."

The group also emphasized the need for multilingual resources to accommodate caregivers from diverse linguistic backgrounds. This would address the inequities experienced by non-native speakers, who often face additional barriers when interacting with complex systems. One participant noted, "Es gibt so viele Menschen, die Deutsch nicht als Muttersprache sprechen, und für sie ist das System noch schwieriger." The introduction of translation services in multiple languages would be a critical step toward fostering inclusivity.

In addition to these practical recommendations, the group discussed the need for increased emotional support for caregivers. This could take the form of peer support groups or mentorship programs where experienced caregivers could assist those just beginning the process. Such initiatives would provide not only practical guidance but also emotional encouragement, helping caregivers feel less isolated. "Manchmal braucht man einfach jemanden, der einen beruhigt und sagt: 'Du schaffst das."'

In summary, the discussions within Focus Group 3 highlighted the profound challenges that family caregivers face when navigating the care allowance system. From the complexity of documentation to the emotional hurdles of bureaucratic processes, caregivers encounter numerous barriers that hinder their ability to access financial support efficiently. The recommendations developed by the group, including the creation of simplified guides, translation support, and enhanced emotional support networks, provide a clear path toward addressing these challenges.

#### Assessing Technical Affinity of Discussion Points in Focus Group 3

A central theme that emerged from the discussions was the caregivers' preference for personal interaction over technological solutions. While the idea of a user-friendly guide could be beneficial, the feedback clearly indicated a strong inclination towards personal assistance.

One participant articulated this sentiment: "Ein ganz ein großes Thema eigentlich durch diesen ganzen Vormittag durch die Gruppe war immer wieder der Wunsch nach dem persönlichen Gespräch, nach der persönlichen Beratung, nicht im Internet suchen müssen…" This reflects the overarching desire among caregivers for direct support that acknowledges their individual needs and circumstances, rather than relying solely on online resources.

In summary, while the development of accessible guides and resources is vital, the preference for personal engagement should inform future approaches. Prioritizing human interaction alongside technological advancements can significantly enhance the experience for caregivers, enabling them to navigate the complexities of the care allowance system with greater ease and personalized support. While future technological tools may serve as valuable supplements, they cannot replace the crucial human element that caregivers seek when receiving assistance within the care allowance system.

As highlighted in previous sections, the study acknowledges that technology is not always the preferred solution. Therefore, this section will not explore or interpret potential technical interventions further. However, it underscores the need for further research to delineate which processes require human assistance exclusively and where technology can be effectively applied.

#### 4.4.4 Reflection on Focus Group 4 - Networking & Knowledge Transfer

Focus Group 4 provided valuable insights into the experiences and challenges of family caregivers, exemplified by the group's persona, Mark, who expressed a strong desire for networking with others in similar situations and easier access to centralized, supportive information.

One of the central themes that emerged was the overwhelming nature of available information and the difficulty in navigating it. Participants highlighted the lack of

#### 4. Design Thinking Workshop

preparedness among caregivers when they suddenly find themselves in caregiving roles, as one participant emphasized: "Pflegende Angehörige können sich auf diese Situation nicht vorbereiten.". This comment reflects the general sentiment that many caregivers feel not well equipped to handle the complexities of dementia care. The group strongly advocated for better access to timely and relevant information through a more centralized platform, with multiple participants expressing frustration over the fragmented nature of support services. As one caregiver pointed out: "Es gibt sehr, sehr viele Angebote auch im Internet. Aber es gibt nur nicht die eine Plattform.". Another echoed this by stating: "Und die Kunst ist, sich als pflegender Angehöriger, der mit der Thematik überhaupt nicht befasst ist, sich da zurechtzufinden.".

Furthermore, the focus group expressed a preference for direct, personal assistance like a "buddy" from individuals who understand their specific circumstances. As one participant explained: "Was wir uns als Angehörige wünschen, ist eine Ansprechperson. Punkt. Keine Organisation, … am allerliebsten einen Buddy, der zuständig ist, … der das alles weiß.", a desire for a more human-centered, personal exchange. The central role of such a support mechanism is further illustrated by the focus group's final tangible outcome, presented in the upcoming figure.

Additionally, participants advocated for flexible mental health support systems, suggesting a voucher system that would allow caregivers to choose their own mental health professionals, as explained: "Was wäre denn, wenn man einfach einen Gutschein übergibt und man kann sich dann selber die Person suchen, wo die Chemie stimmt.". This approach would provide caregivers with autonomy and ensure that they receive the emotional support they need from professionals they feel comfortable with.

Finally, the significance of peer group gatherings was emphasized, with discussions centering on preferences for communication and interaction modes. Both in-person and online formats were recognized for their distinct advantages. In-person interactions were appreciated for offering focused attention and a break from the home environment: "Die Möglichkeit eines Ortswechsels, das auch manchmal entlastend ist, wenn ich die vier Wände verlassen kann. Die ungeteilte Aufmerksamkeit, die ich dann dort habe...". While the convenience and accessibility of online platforms were also acknowledged, particularly for caregivers with limited mobility or other constraints: "Es ist ortsunabhängig, es ist wetterunabhängig.". This suggests that a hybrid model combining both in-person and online support would best meet the diverse needs of caregivers.

90



Figure 4.8: Design Thinking Workshop Outcome of Focus Group 4 - Workshop Phase II.

#### Assessing Technical Affinity of Discussion Points in Focus Group 4

With regard to the discussions in Focus Group 4, a clear division emerged between areas where technological solutions were welcomed and those, where participants preferred more human-centered approaches. While participants expressed a need for digital platforms in some areas, the importance of physical presence and human connection was likewise emphasized, underscoring the limitations and desired boundaries of technological interventions.

In particular, participants expressed a strong preference for human-centered solutions in areas requiring emotional support. A proposed system featured a human *buddy* to guide family caregivers, emphasizing the need for consistent, personalized support over digital interactions, as previously noted. This buddy system would not only provide practical guidance on caregiving questions but also foster a peer-to-peer initiative to offer mutual emotional support.

In contrast, settings, in which participants sought technological solutions to address the previously identified problem space, focused on establishing a more organized and accessible digital infrastructure.

#### Areas Where Technology was Desired:

- Centralized Information Platform: Participants emphasized the overwhelming and fragmented nature of the current information landscape for family caregivers. Thereby, a centralized digital platform was proposed as a solution, offering a user-friendly way to navigate various resources. Such a solution might aggregate all relevant information, ranging from healthcare resources to local peer support groups, facilitating caregivers' access to necessary information.
- **Digital Peer Support Networks:** The need for peer support was clear, and participants welcomed the idea of technology playing a role in facilitating these connections. A digital solution, such as an app or online community, could allow caregivers to connect with others who have similar experiences, creating a space for mutual support. An AI-driven matchmaking system could pair individuals based on shared experiences and needs, fostering meaningful interactions.
- Voucher System for Mental Health Support: Participants suggested a digital solution for mental health services, such as a voucher system that allows caregivers to select their own mental health professionals. This idea could be implemented via an online platform where caregivers can browse mental health professionals, filter by specialty and location, and book appointments directly.
- Hybrid Communication Solutions: While physical interactions were appreciated, the flexibility of digital platforms for communication was likewise highlighted. Participants indicated that a hybrid model – offering both, online and in-person
communication options – would best meet their needs. Video consultations or telecare services, accessible through a shared platform, would allow caregivers to choose the mode of communication based on their preferences or circumstances.

In summary, Focus Group 4 indicated a clear demand for technological solutions in areas such as centralized information platforms, digital peer support networks, and hybrid communication systems. These solutions would make caregiving more manageable by offering flexible, accessible resources and connections. However, when it comes to emotional support, such as the desire for a physical buddy, technology was seen as less appropriate. In these cases, participants highlighted the irreplaceable value of human interaction and the limitations of digital tools in fostering trust and emotional bonds.

## 4.5 Conclusion

The diversity of participants and their unique circumstances – illustrated through the personas – offered a broad range of perspectives on informal caregiving in Austria. This diversity was instrumental in uncovering the various ways caregivers navigate their roles. For instance, discussions revealed how factors such as the stage of dementia and the caregiver's relationship to the care recipient influenced their experiences and needs. Despite these differences, common patterns emerged that could be translated into technical requirements. The shared insights from these discussions were particularly valuable in generating practical solutions applicable to a wide range of caregiving scenarios.

## 4.5.1 Overview of Key Themes Emerging from the Focus Groups

The focus group sessions not only yielded valuable exchanges and ideas but also enabled deeper insights into the dynamics of caregiving that might not have been captured through other research methodologies. Hence, the workshop effectively synthesized insights from all four focus groups, leading to the identification of several key themes.

Focus Group 1 examined the challenges faced by family caregivers in the early stages of dementia care, highlighting the overwhelming array of available resources that are often difficult to navigate. To address these challenges, participants emphasized the need for a *One-Stop-Shop* platform that consolidates essential information in a user-friendly format, enabling caregivers to efficiently access the support they require. This centralized digital platform should organize information hierarchically, simplifying the process of locating both general and specific resources.

Furthermore, the incorporation of AI-based features would allow for the delivery of personalized content tailored to individual needs. Integrating functionalities such as reminders and digital forms for legal processes could significantly reduce administrative burdens. Additionally, the group advocated for the use of info screens in public spaces to enhance awareness about dementia and underscore the vital role of caregivers, thereby fostering a more supportive community. In conclusion, these insights highlight the

#### DESIGN THINKING WORKSHOP 4.

potential for a comprehensive platform that combines informational, legal, and emotional support, significantly improving the caregiving experience.

In Focus Group 2, participants aimed to design a digital calendar and checklist that would streamline caregiving tasks and enhance organization. They identified three primary challenges faced by caregivers: documentation, organization, and health management, along with the critical aspect of self-care. Participants emphasized the ambiguity surrounding necessary documentation, suggesting the creation of structured templates and checklists to clarify what needs to be recorded. Additionally, they highlighted the complexities of organizing care, advocating for a digital platform that allows caregivers to break down tasks into manageable components. The group also stressed the importance of self-care, urging caregivers to prioritize their well-being to prevent burnout while managing their loved ones' health.

To address these challenges, the group proposed several innovative tools and strategies. They envisioned a shared digital platform featuring a calendar and to-do list to enhance organization and facilitate communication among family members. Participants suggested incorporating interactive features, such as reminders for significant dates and visual cues, to engage caregivers and enrich their interactions with care recipients. They also recognized the value of self-reflection journals within the digital tool, allowing caregivers to document their experiences and emotions.

Focus Group 3 shed light on the challenges family caregivers encounter when navigating the care allowance system, particularly due to the complexity of the application process. Participants voiced frustration over bureaucratic obstacles, highlighting the confusion caused by unclear eligibility criteria. In response, the group strongly advocated for the development of a simplified, user-friendly guide to make the process more tangible. This guide would clarify complex terms and provide step-by-step instructions to reduce the stress and uncertainty caregivers often face.

Another key theme that emerged was the caregivers' strong preference for personal assistance over digital solutions. Thereby, many participants emphasized the need of individualized support by experts, to help them through the application process. While digital tools were acknowledged as useful, the consensus was that they could not replace the value of human interaction, particularly in providing emotional support.

Focus Group 4 highlighted the overwhelming and fragmented nature of information available to family caregivers, leading to a strong call for a centralized digital platform to streamline access to necessary resources. Participants also expressed a clear preference for human-centered support, particularly through a proposed "buddy" system, which would offer personalized emotional and practical guidance, ensuring consistency in caregiving. While participants welcomed technology for organizing information and fostering peer support, they also emphasized the irreplaceable value of human interaction in areas requiring emotional support. Digital tools, such as online peer networks and hybrid communication models, were seen as useful for flexibility and accessibility, but in-person connections remained crucial, particularly in fostering trust and providing mental health support.

Overall, participants exhibited a high level of openness and a willingness to collaborate in a co-design manner, as evidenced by the tangible outcomes, achieved during the workshop. The deliberate composition of the groups – guided by findings from preliminary interviews and the background knowledge of the invited participants – significantly enhanced the quality of the discussions. This structured approach facilitated a balanced distribution of participant profiles, fostering smooth progression and a clear, shared vision within the given problem space.

Despite the comprehensive nature of the topics, participants successfully addressed all areas outlined in the task description. Both family caregivers and experts maintained a shared understanding of the main objectives. By the end of the workshop, all groups delivered tangible outcomes using the materials provided in the design thinking boxes. While some groups, such as Focus Group 1, prioritized simplicity and depth of information, others, like Focus Group 2, creatively employed colors and sticky notes to design a visually engaging, color-coded calendar.

The final presentation further facilitated networking and personal exchanges, with participants remaining for an additional 1.5 hours after the official event closure, demonstrating a strong desire for continued interaction and collaboration.

As part of future work, it is essential to validate the findings through the completion of the testing phase to fully align the solutions with user expectations. This validation was not completed due to time constraints and the necessity of additional design sessions, which would exceed the scope and focus of the present study.

## 4.5.2 Key Limitations and Ethical Considerations of the DT Workshop

As discussed in section, *Limitations in Workshop Data Collection and Analysis*, including additional coordinators could have improved data collection efforts. However, this approach might significantly alter the informal nature of the event, which is crucial for fostering cohesion and trust among participants. Therefore, future workshops should carefully weigh the actual advantages of enhanced data collection against the risks of diminishing participants' openness, disrupting group dynamics, and compromising overall comfort.

Ethical considerations were vital due to the sensitive nature of the discussion topics within the focus groups. Consequently, a comprehensive validation of the workshop materials was conducted in collaboration with the study's ethical mentor, alongside rigorous oversight of the overall design and execution of the methodology. Furthermore, the ethical mentor was present throughout the event to ensure compliance with ethical standards. In the course of the workshop, participants were provided with informed consent as included in *Appendix B.2: Workshop Participant Consent Form*, which ensured adherence to legal requirements by clearly communicating their rights.

In summary, the insights gained from the Design Thinking Workshop have significant implications for designing future user-centric Assistive Technologies for family caregivers of individuals with dementia (PwD). The workshop generated a wealth of information on behavioral patterns and group dynamics, uncovering key drivers while also achieving tangible outcomes through participant engagement.

Thereby, a collaborative design approach that incorporates diverse stakeholders facilitates the formulation of technical requirements. This approach ensures alignment with the needs of the target group through numerous feedback loops, ultimately enhancing the relevance of the solutions in real-world settings.

# CHAPTER 5

# Use Case Development for User-Centered Design Concepts

In the final phase of the present research, a use case and its associated scenarios will be selected and further refined to address the requirements outlined in earlier research phases. These requirements specifically target family caregivers of individuals with dementia and are primarily based on insights gained from the conducted Design Thinking Workshop. By concentrating on the specific contexts in which caregivers operate, the analysis will aim to capture their unique needs and the functional requirements necessary for developing effective Assistive Technologies.

These scenarios, built around the selected use case, will incorporate user-centered design solutions in the form of technical requirements tailored to the problem space. Thereby, the presented methodical framework will identify essential features and support mechanisms while also aiming to uncover opportunities for innovation, ensuring that the development of concepts aligns with real-world conditions and technical adaptability.

Consequently, the developed requirements are anticipated to improve future ATs and outcomes for family caregivers by facilitating optimized efficiency in their caregiving roles, while also generating positive effects for other stakeholders, as care recipients.

## 5.1 Introduction

In the previous chapter, various directions emerged from the four focus groups, highlighting both technical affinity and the necessity for further investigation. However, to maintain a sharper focus, this study will concentrate on the findings and problem space defined in Focus Group 2. This selection is justified for several reasons.

Firstly, Focus Group 2 yielded the most mature and refined outcomes, presenting a clear vision for user requirements. In contrast, the other focus groups produced a broader range of ideas and solutions, indicating that additional Design Thinking sessions would be needed to achieve more concrete results. Thus, selecting another focus group would likely lead to a loss of content, given the complex nature of the generated ideas.

Secondly, Focus Group 2 demonstrated the highest level of technical affinity, providing a sound foundation for the formulation of technical requirements. These requirements will be articulated in the form of a use case and associated scenarios in the current chapter.

Now, linking the present chapter to the *Double Diamond Model*, the study's research framework model, it transitions into the fourth phase, referred to as the *deliver phase*. In the preceding phase, the emphasis was on generating a broad array of potential solutions. In contrast, *Chapter 5* will focus on a detailed analysis of a specific problem space identified by Focus Group 2.



Figure 5.1: Double Diamond Model - Phase 4: Deliver Source: Created by Author based on Double Diamond Model by Design Council[Des24b]

Hence, this chapter includes the evaluation of the solutions developed in the previous phase, placing particular emphasis on refining the most promising features. Consequently, the fourth phase delivers a concrete use case and associated scenarios for a proposed digital calendar that addresses the specific requirements of family caregivers. By adopting a convergent approach, this phase promotes a more focused synthesis of these technical requirements.

To provide a brief recap of the findings from Focus Group 2 during the Design Thinking Workshop, several key problems and corresponding solutions proposed by participants emerged. The following summary highlights selected features that encapsulate these insights:

#### Key Findings from Focus Group 2

• *Problem Space:* Documentation Uncertainty Family caregivers often encounter difficulties in identifying the necessary information required for the efficient completion of administrative tasks related to care documentation.

#### Potential Solution: Structured Checklists

Developing structured checklists that clarify documentation needs, ensuring caregivers effectively track essential information.

• Problem Space: Health Management Responsibilities

Caregivers face significant challenges in managing the health-related needs of care recipients while balancing their own well-being.

Potential Solution: Health Management Features

Integrating health management features – such as scheduling doctor's appointments – along with reminders into caregiving tools to streamline the health-related needs of care recipients while also promoting caregiver self-care – as through alerts that prompt them to schedule personal appointments or allocate time for leisure activities.

• Problem Space: Difficulty in Task Decomposition and Distribution

Caregivers often struggle to break down complex caregiving tasks into manageable components and effectively delegate these responsibilities among other family members involved in care.

#### Potential Solution: Interactive Task Management Features

Developing interactive task management features that enable caregivers to decompose larger tasks into smaller, actionable steps and actively distribute responsibilities to others.

• Problem Space: Need for Self-Reflection

Caregivers have limited opportunities to reflect on their own experiences and emotions, which impacts their well-being.

#### Potential Solution: Self-Reflection Journals

Including a journaling feature within caregiving tools that allows caregivers to document their feelings, helping them process their experiences and track changes over time in care.

As outlined in the findings above, a broad range of features were articulated for potential integration into digital calendars to effectively address the challenges faced by family caregivers. The inclusion of these features is anticipated to enhance both, organizational efficiency and task management, thereby optimizing caregiving workflows by leveraging Assistive Technologies.

## 5.2 Methodological Framework for Use Case Development

Use cases represent a valuable tool within software engineering, offering a systematic approach to the documentation of "functional requirements of a software system" [TG15]. They are instrumental in ensuring that user needs are thoroughly understood and effectively addressed throughout the implementation life cycle. Thereby, the identification of specific user requirements is essential, necessitating their systematic organization and translation into technical specifications that inform both the design and development of future systems. [TG15]

Complementing the use case – specified in the upcoming section – that delineates the overall problem space, scenarios will be employed to ensure a user-centered design and facilitate a comprehensive investigation of the identified challenges.

Scenarios illustrate real-world problem settings, events, or actions in which users engage, thereby enhancing the understanding of user interactions, behavioral patterns, and practical needs within specific contexts. Each scenario represents a realistic situation derived from the use case, underscoring its significance to the proposed solution.[TRR13] In this context, scenarios will be employed to ensure that the proposed solution and technical requirements effectively align with the previously identified needs of family caregivers.

#### 5.2.1 Design of the Use Case

To establish a logical progression and link between the distinct research phases of the present study, this chapter will utilize the previously presented persona and the defined problem space of Focus Group 2.

#### Use Case Specification

The proposed use case, employing David's character from the second focus group, is outlined as follows:

David – 75 years old – is caring for his wife, who has been diagnosed with advanced dementia and requires constant care. His primary objective is to balance his caregiving duties with personal responsibilities, ensuring that his wife receives the best possible care. However, David struggles to keep track of his wife's medical appointments, medication schedules, and other caregiving tasks while also managing his personal commitments and mental well-being.

Without a centralized tool to assist him, he often feels overwhelmed and disorganized, which can lead to potential gaps in care.

Furthermore, David and his wife have two children who work full-time but are open to assist. However, communication barriers occasionally arise due to various factors, including David's perception of being left alone in caregiving, especially since their children work full-time, and his ongoing hesitation to seek active support. This dynamic can lead to conflicts among the family members, hindering effective collaboration in the caregiving process.

Consequently, the goals and expected outcomes encompass the following:

By utilizing a digital calendar along with the proposed features, David will be better equipped to manage his caregiving responsibilities while balancing his personal commitments. This tool aims to enhance both organization and coordination, ultimately leading to improved care for his wife and a more balanced life for David as a family caregiver.

Focusing on the presented use case, scenarios will be derived and outlined in the forthcoming sections, accompanied by technical requirements to ensure a user-centered design.

## 5.3 Optimizing Informal Caregiving through Tailored Digital Calendar Solutions

The use of digital calendars in everyday settings, encompassing both personal and professional purposes, has become widespread in the digital era. These tools offer a wide range of features that often surpass the capabilities of traditional paper calendars. Features vary by platform (e.g., Google Calendar, Apple Calendar, Microsoft Outlook) and include key functionalities such as event scheduling and reminders, multiple calendar views (e.g., weekly, monthly, yearly), and collaboration options.[Goo24][App24][Mic24]

Within the context of this study, additional features articulated by family caregivers and experts, specifically pertaining to the caregiving role, have been identified.

Consequently, this section attempts to leverage and expand upon the existing features of digital calendars. It will incorporate potential enhancements that study participants either expressed as desires or that emerged as relevant based on insights gained from the informal caregiving landscape.

To illustrate these concepts in a more tangible manner, scenarios will be developed utilizing the previously introduced character of David, who serves as a representative potential user.

#### 5.3.1 Scenario 1

As the primary caregiver for his wife, David maintains a comprehensive overview of her schedule and activities. To prioritize his mental health, he plans a one day hiking trip. Unfortunately, this break coincides with a scheduled doctor's appointment for his wife, a conflict he only realized during his train ride to the hiking spot. Aware that he won't be available, David decides after long considerations to involve his children in rescheduling the appointment. To streamline this process, David grants his children access to his shared calendar, ensuring they can view and edit all relevant information in real time. By having access to this comprehensive and organized calendar, David's children can quickly identify available slots and reschedule the doctor's appointment without any conflicts or confusion. The integrated notification system alerts them to any changes, ensuring that everyone stays informed. This way, David can focus on his mental well-being while his children efficiently manage the logistics of their mother's care, enhancing coordination and communication among all family members involved.

#### **Functional Requirements of Scenario 1**

Given the complexity of caregiving situations, seamless coordination between multiple stakeholders is crucial. Thereby, a key feature of a digital calendar is the ability to share access among multiple stakeholders, ensuring that everyone remains informed about caregiving schedules, as demonstrated in the case of David and his children.

Based on the family dynamics and given setting, informal and formal caregivers or healthcare providers, among others, can be granted appropriate access to care recipients' calendar.[CEN<sup>+</sup>17][Mic24]

#### Management of Sensitive Data

Equally important is the definition of user groups and access levels, determining the extent to which each user can view or edit entries in the shared calendar. For example, different users, such as family members or healthcare providers, can have customized views, displaying only the tasks relevant to them. The technical implementation could leverage role-based access control (RBAC) frameworks for dynamic permission handling, ensuring sensitive information, such as medical details, is managed securely.[BMS<sup>+</sup>23]

#### Real-Time Synchronization and Healthcare System Integration

While ensuring that multiple users have access to the system, it is equally important to maintain the most up-to-date information for efficient appointment scheduling. Therefore, implementing real-time synchronization within the digital tool is essential, as it effectively prevents scheduling conflicts and missed appointments. [CEN<sup>+</sup>17]

To further optimize caregiving efficiency, the tool could integrate with existing healthcare management systems, such as Austria's ELGA, which facilitates streamlined access to health records. By establishing interoperability with healthcare provider systems, the tool would enable seamless synchronization of medical appointments and automated reminders, significantly reducing the administrative workload on caregivers.[SCO24][Fed20] For recurring doctor's appointments, autonomous scheduling functionality could be im-

plemented, dynamically adhering to blocked times and predefined user preferences set by David, ensuring a smooth and conflict-free scheduling process.

#### Embedded Communication Channels

Another critical aspect represents enhanced communication. Given that many family caregivers noted in the interviews, using WhatsApp for coordination, an integrated communication channel could be valuable. Built-in messaging or notification systems would improve communication by alerting users to schedule changes or task completions. Furthermore, this integrated channel could facilitate the transfer of documents, such as medical prescription details, reducing logistical hurdles in obtaining relevant information.

#### Features for Enhanced User Experience and Customization

The last aspect pertains to user experience. On days when caregivers allocate time for their personal well-being – like David in the present scenario –, it is essential to visually represent this commitment through the calendar interface. To fulfill this requirement, the digital calendar must incorporate features that allow users to switch between different calendar views, enabling them to seamlessly integrate or conceal other users' appointments within their own calendar environment. This functionality not only enhances usability but also empowers caregivers to maintain a clearer focus on their personal priorities while effectively managing their caregiving responsibilities. Moreover, the integration of an advanced color-coding system can substantially enhance user experience and organization. This feature should empower users to dynamically customize and predefine color codes linked to specific individuals or activities, thereby fostering a more structured and coherent overview of their schedules. To ensure flexibility, the system should allow users to save and apply these color configurations across different calendar views, enhancing both accessibility and efficiency in schedule management.[Mic24][Goo24][App24]

#### 5.3.2 Scenario 2

As David's wife's health condition continues to decline, he considers applying for a higher care allowance. One evening, in preparation for an upcoming doctor's appointment where her condition will be assessed, he realizes that he hasn't documented crucial information about her recent medication changes, behavioral patterns, or care routines in general. Reflecting on a conversation he had with fellow caregivers, he remembers their shared struggle with determining what details to track for effective care. Inspired by their suggestion to utilize structured checklists, David decides to explore a digital calendar designed specifically for caregivers. With this tool, he sets reminders to document essential information, such as medication schedules and daily observations, aiming to ensure he is fully prepared for the appointment and able to provide comprehensive updates on his wife's condition.

#### **Functional Requirements of Scenario 2**

In the scenario presented, David's uncertainty about what caregiving details need to be documented when applying for a higher care allowance reflects a common challenge among caregivers. This issue was further emphasized during the interviews and Design Thinking Workshops, where the need for structured and consistent care documentation emerged as a central theme in caregiving practices.

#### Advanced Documentation Functionalities

To address this, digital calendar solutions could incorporate advanced documentation functionalities, such as integrated checklists or templates, similar to those offered by the tool, *Alles Clara*. These templates would allow users to insert data quickly, based on predefined categories essential to caregiving – such as observations, medication logs, and health changes. Standardizing the documentation process in this way would reduce inconsistency, while ensuring the completeness of caregiving records.[All24][Lau24]

#### Reminders and Notifications

Additionally, the tool could feature reminders and alerts, prompting caregivers to document specific information at appropriate times. For example, reminders could be linked to predefined routines, ensuring that critical updates—such as medication schedules or notable changes in health—are recorded promptly and systematically.[Goo24][Mic24]

#### **Reporting Features**

To enhance the utility of the digital calendar, it could include functionality to generate reports or documents that compile caregiving data based on predefined health metrics. These documents could be dynamically adapted to serve different purposes, such as applying for care allowances or creating monthly reports that track health management trends. Caregivers would have the flexibility to customize the time frame and level of detail, with the system automatically consolidating data from notes and reminders into a comprehensive, structured document. [Lau24]

#### Expanding Input Modalities for Improved Accessibility

Additional features could focus on expanding input modalities to enhance usability. Given that the documentation process can be time-consuming and some users may lack familiarity with digital tools, integrating speech recognition would be a valuable enhancement. Thus, a speech-to-text feature would allow users to document caregiving tasks verbally, providing a more accessible and efficient method for recording information, particularly for those who find typing cumbersome or for individuals with disabilities.[DBB<sup>+</sup>23]

Thereby, digital calendar solutions could be enhanced by incorporating advanced documentation functionalities, such as checklists and templates for structured data input, reminders for timely updates, and reporting features for generating comprehensive caregiving reports. Furthermore, expanding input modalities would significantly improve accessibility, enabling users to document caregiving tasks verbally.

#### 5.3.3 Scenario 3

For caregivers like David, the responsibility of caregiving can often feel overwhelming, yet asking for help is sometimes emotionally challenging. He tends to manage most caregiving tasks on his own, fearing that he might burden others. However, as these responsibilities

grow more demanding, David begins to recognize the need for shared support. He envisions a tool that offers a clear, visual overview of his caregiving commitments, helping him first identify the tasks he is performing—perhaps even unintentionally—yet still requiring significant effort.

This transparent visualization could empower others, like family members or fellow caregivers, by making visible where their support might be needed, especially when certain tasks go unnoticed by those around him. By displaying the full range of day-today responsibilities in a digital calendar, the tool would transform the act of requesting help from a burdensome task into an opportunity for collaborative caregiving. David believes this approach would encourage a culture of mutual support, reducing his sense of isolation and making it easier to seek assistance. At the same time, it would enable others to contribute in a more proactive and meaningful way.

#### Functional Requirements of Scenario 3

The scenario highlights two primary needs: self-awareness of caregiving tasks and effective task distribution. Both were frequently reported by participants during interviews and design thinking workshops, where the reluctance to actively seek help emerged as a recurring theme.

A digital calendar addressing this scenario should enable the visibility of all caregiving tasks, including those that might be overlooked by secondary caregivers or family members. This transparency allows other participants to independently identify areas where they can meaningfully contribute according to their own schedules. Moreover, such a system would encourage spontaneous support, especially in situations where geographic distance limits direct involvement, fostering a more flexible and responsive caregiving network. To achieve this, key functional elements should include the following:

#### Task Ownership & Advanced Task Management

The interface should visually represent time-bound tasks, with clear indicators of task ownership. This transparency helps distribute responsibilities effectively and encourages self-appreciation by allowing caregivers like David to track their own contributions and even optimize them.

For tasks that involve multiple steps, such as a doctor's appointment of the care recipient, the tool should integrate checklists. For instance, a doctor's visit might include preparing care documentation, completing forms, and requesting a prescription refill. These sub-tasks might be delegated to different family members, enhancing overall task management and efficiency.

To further simplify caregiving, machine learning algorithms could be employed to suggest sub-tasks based on historical data and recurring caregiving patterns. For example, if certain steps might be associated with specific tasks, the digital calendar could automatically propose these as part of a checklist, making task decomposition more intuitive and context-aware. [CEN<sup>+</sup>17]

#### Context-Aware Task Identification

Context-aware systems could play a significant role in identifying and suggesting new tasks based on the evolving needs of the care recipient. For example, if a significant change in the recipient's mobility is detected, such as a decline in physical activity through wearables or reported health data, the system could automatically suggest tasks like scheduling a physiotherapy session. This feature should also include reminders or notifications, alerting caregivers to these new tasks or changes in the recipient's condition, ensuring timely interventions and optimal care management. [ZBF<sup>+</sup>18]

#### Custom Task Categories and Hierarchies

Users should be able to create custom categories, such as *family matters*, *daily care routines*, *events*, or *health-related tasks*, to better organize related activities. Subcategories like *neurologist appointment* or *Café Zeitreise* would offer a more detailed breakdown, enabling a granular view of tasks and commitments. Machine learning algorithms could further streamline this process by suggesting relevant categories and subcategories based on historical data and user behavior, ensuring that the caregiving structure remains intuitive and personalized. In addition, predictive analytics and reporting tools could offer insights by identifying patterns or tracking time spent per activity, represented through visualizations such as graphs, to optimize caregiving workflows and decision-making.

In summary, by incorporating these features, the tool would not only improve caregiving task distribution but also foster a more collaborative environment where caregivers feel supported without the pressure of constantly directly asking for help.

#### 5.3.4 Scenario 4

David often finds himself overwhelmed by the demands of caregiving, struggling to maintain a balance between supporting his loved one and taking care of his own mental well-being. As he frequently loses track of the time he has for leisure and self-reflection, he envisions a digital tool that could help him manage these competing priorities. This tool would incorporate a journaling feature, allowing David to document his thoughts, emotions, and memories while also providing a space for self-reflection. Additionally, he desires the integration of reminders that prompt him to allocate time for personal activities, especially during particularly busy weeks. By facilitating these practices, David hopes the tool will not only enhance his caregiving experience but also promote a healthier, more balanced life, ensuring that he can provide support to his loved one without sacrificing his own well-being.

#### **Functional Requirements of Scenario 4**

Integrating journaling capabilities into the caregiving tool would empower caregivers like David to document their experiences and emotions. This feature would serve a dual purpose: providing a record of changes in the care recipient's condition and offering caregivers a space to process their feelings, fostering emotional stability through selfreflection.

#### Task Prioritization with Visual Indicators

The tool should include a system of visual indicators—such as icons or a scoring system—to distinguish between high-priority tasks (like doctor appointments) and lower-priority tasks (such as household chores). This feature would enhance time management by allowing caregivers to allocate time for personal activities based on the urgency of their responsibilities. Additionally, machine learning algorithms could assist in assessing a balanced distribution of tasks while ensuring that self-care activities are scheduled and respected. If a caregiver neglects these personal time slots, the digital calendar should issue reminders to help them stay on track. [CEN<sup>+</sup>17]

#### Interactive Reminders and Positive Reinforcement

Incorporating interactive elements into the caregiving tool—such as reminders for significant dates and notifications of fond memories—could greatly enhance the caregiving experience. By drawing information from care documents embedded within the digital calendar, both family caregivers and care recipients could be reminded of positive moments, fostering emotional connections and enhancing the care recipient's capacity to recall and celebrate joyful experiences.[ZBF<sup>+</sup>18]

#### Features to Strengthen Emotional Bonds

Lastly, features designed to promote emotional connections could be invaluable. Allowing caregivers to set reminders for significant dates, such as anniversaries and birthdays, as well as to include personal images, could cultivate a more supportive and enriching environment for both caregivers and care recipients. This shared focus on meaningful moments may strengthen emotional bonds and positively impact the mental well-being of everyone involved.

## 5.4 Conclusion

Drawing on insights from Focus Group 2 and earlier research phases concerning the development of a digital calendar and checklist tool, several key aspects were articulated by highlighting specific caregiving contexts that utilize the persona characteristics of David, to guide the implementation of future Assistive Technologies.

This chapter presented the developed use case, complemented by scenarios that outlined a range of functional requirements. These requirements underscored the necessity for a sophisticated tool that not only addresses the organizational challenges faced by family caregivers – challenges that might seem manageable with conventional digital calendars such as Google Calendar or Outlook – but also integrates tailored features.[Goo24][Mic24] In this context, it is imperative for the tool to integrate functionalities that address the unique and evolving needs of care recipients across diverse caregiving scenarios. This includes context-aware features and task distribution management capabilities that foster a balanced and collaborative environment among caregivers.

Given that family caregivers often belong to older age groups, as represented by the persona of David, it is essential to prioritize accessibility and usability for aging caregivers.[PEHR21][ös24][SMS13] Usability and accessibility are critical for ensuring the effectiveness of the tool and enhancing caregiving outcomes. Future assistive technologies should provide a simplified user interface with intuitive interaction pathways, while also addressing potential barriers or disabilities that caregivers may face. Customization options, such as adjustable font sizes, clear icons, and reduced complexity, should be implemented to accommodate users who may not be tech-savvy, thereby ensuring accessibility for all.[SMS13][SV22]

Additionally, features such as voice command integration could significantly enhance the user experience. Implementing voice recognition technologies, such as those offered by Amazon Alexa, would enable aging caregivers like David to interact with the digital calendar in a hands-free manner, further streamlining their caregiving tasks.[JDD<sup>+</sup>22]

#### 5.4.1 Navigating Data Privacy and Ethical Considerations in Digital Calendars for Caregivers

Given the sensitive nature of the caregiving role – particularly in cases involving health conditions such as advanced dementia – ensuring data privacy and addressing ethical concerns in the design of future Assistive Technologies must be a central focus.[BMB<sup>+</sup>17]

This is especially critical in scenarios, involving multiple stakeholders. Therefore, in addition to functional requirements, special attention must be paid to *end-to-end encryption (E2EE)* practices. In essence, all communications and task updates within the AT should be encrypted using applicable protocols to protect sensitive medical and personal information.[VSP23]

Moreover, secure data handling and sharing must align with data governance standards and best practices within the realm of medical data. Thereby, implementing *role-based access control* ensures that only authorized individuals can access or manipulate specific calendar entries. This approach not only protects the privacy of both, caregivers and patients, but also provides access at a defined granularity for additional stakeholders.[BMS<sup>+</sup>23]

As an overarching consideration, ethical aspects must be addressed throughout the entire design process, especially when incorporating AI-driven features in assistive devices. Key stakeholders, such as care recipients with progressive dementia, may lack the capacity to comprehend how their data is managed when relying on digital, shareable solutions. Therefore, the legal implications of involving multiple actors in this context must be carefully investigated to ensure compliance with ethical standards.[BMB<sup>+</sup>17]

In summary, the design of future Assistive Technologies for digital calendars, along with the incorporation of features such as checklists and documentation capabilities, should prioritize role-based functionality, enhanced communication, task prioritization, and accessibility to optimize the management of caregiving responsibilities. The integration of AI-driven automation, secure data management, and comprehensive ethical considerations holds the potential to create a more efficient and inclusive organizational tool. Consequently, empowering family caregivers – such as David – to achieve a more balanced task management of their personal and caregiving responsibilities while facilitating improved collaboration among all stakeholders involved in the care process.

# CHAPTER 6

# **Discussion and Conclusion**

In light of the global increase in dementia prevalence – expected to double by 2050 in Austria – and the persistent shortage of formal caregivers, the role of family caregivers is becoming increasingly vital. Research shows that individuals with dementia prefer to remain in their home environments for as long as possible; currently, 80% of people in need of care rely on informal caregivers in Austria. This statistic highlights the essential role family caregivers play and indicates that their involvement will be even more critical given the anticipated demographic changes.[PEHR21][PBL<sup>+</sup>20][Int24b][SMS13][Sab15][ös24]

As the study demonstrated, a strong desire for the integration of Assistive Technologies within practical caregiving contexts was expressed by family caregivers of individuals with dementia in Austria. Through careful analysis of the obtained requirements derived from this research, the translation of these needs into functional requirements for future ATs was achieved. Equipping family caregivers with tailored Assistive Technologies holds significant potential to enhance various facets of the caregiving ecosystem. Such integration could optimize the roles of family caregivers, while improving their mental well-being – identified as one of the most significant burdens. This, in turn, would positively impact care recipients. Closing the loop, associated stakeholders and state systems may benefit from substantial relief due to the optimized support provided by family caregivers.

## 6.1 Research Outcomes in Overview

To explore the identified problem space, the study formulated two leading research questions and utilized the *Double Diamond Model* as a research framework. This model provides a structured approach to guide the process through four phases while alternating between divergent and convergent thinking.[Des24b]

#### Key Findings on Approaches and Support Systems for Family Caregivers

The first research question focused on examining existing approaches and support systems for family caregivers of people with dementia in Austria.

This was achieved through a comprehensive analysis of current literature and relevant research projects, laying a solid foundation for the study. In addition to identifying a significant gap in the available, context-relevant Assistive Technologies, further pain points have been uncovered, emphasizing the research relevance of this domain. Findings indicate that many individuals transition into caregiving roles without being aware of it, underscoring the importance of proper recognition and a efficient support frameworks. Additionally, informal caregivers often face the challenge of balancing professional responsibilities with caregiving duties, leading to significant time constraints, limiting their access to essential tools and information. Financial limitations further complicate the caregiving process. Consequently, family caregivers are often compelled to make critical decisions influenced by their financial circumstances. Particularly when evaluating options for hiring a privately financed professional caregiver, as state-funded options may not be applicable due to eligibility criteria. Moreover, the informal role of family caregivers remains frequently undervalued in society, leading to significant physical and psychological burdens that contribute to a cycle of stress. These interrelated challenges highlight the critical need for targeted research focused on enhancing support mechanisms and developing tailored ATs.

Complementing the previously outlined findings, interviews were conducted with 12 family caregivers and 6 experts. The experts included representatives from organizations such as the Gesundheit Österreich GmbH (GÖG), Interessengemeinschaft pflegender Angehöriger, the interdisciplinary Young Carers Project Team – which comprised professionals from FH Oberösterreich and Sozialministerium –, and TU Wien. Additionally, informal discussions were held with project leads at Caritas Pflege and Fonds Soziales Wien, which – although not formally recorded – significantly contributed to the depth of the present study. These organizations play a pivotal role in providing support to family caregivers in Austria, besides further dominant institutions.

Both focus groups yielded valuable insights into the multifaceted challenges faced by family caregivers. Key themes that emerged from the analysis highlighted issues including difficulties in identifying the right resources, challenges in organizational matters and time management, efficient task distribution and the overwhelming nature of the application process for care allowance. Additionally, family caregivers reported feelings of social isolation, stress, and burnout, emphasizing the urgent need for comprehensive support systems that address both the emotional and logistical aspects of caregiving. Furthermore, the often overlooked group of young carers and the gender imbalance in caregiving roles – indicating that caregiving tasks disproportionately fall on women – emerged as critical themes.

#### Key Findings on Innovating Technologies and Support Structures through Design Thinking

While the second research question investigated the process of innovating technologies and support structures through the principles of Design Thinking.

Building upon the previously attained findings, the next phase focused on the central component of the study: the execution of a Design Thinking Workshop. This workshop aimed to foster ideation and generate innovative solutions in a co-design manner by bringing together an interdisciplinary group of 12 active participants, distributed across 4 distinct focus groups. Each focus group concentrated on a specific problem space during the workshop, yielding valuable insights into caregiving dynamics and tangible outcomes. Focus Group 1 examined the challenges faced by family caregivers in the early stages of dementia care, emphasizing the need for a One-Stop-Shop platform to consolidate essential information and simplify access to resources. Thereby, incorporating AI-based features revealed potential for personalized and targeted content. Additionally, promoting public awareness was identified as crucial. Focus Group 2 aimed to design a digital calendar to streamline caregiving tasks, identifying key challenges in care documentation, organization, health management, and self-care. Revealing itself as the most mature and technically oriented solution developed, some ideas included the proposal of a shared digital platform with interactive features to enhance caregiver engagement along with task distribution features. Based on the workshop outcomes, numerous further features were extracted, allowing for their technical translation. Focus Group 3 highlighted the complexities of the care allowance system, advocating for a simplified guide and emphasizing the need for personal assistance from experts rather than solely relying on digital solutions. Focus Group 4 called for a centralized digital platform to address the overwhelming and fragmented nature of information available to caregivers and proposed a physical *buddy* system for personalized support.

Overall, the workshop fostered a collaborative environment, with participants demonstrating a high level of openness to co-design solutions, significantly enhancing the quality of discussions and outcomes.

Consequently, these combined sources informed the development of concrete improvement suggestions and concepts for future Assistive Technologies. In this context, the most technically oriented problem space was selected, represented by the outcomes of Focus Group 2. This led to the development of a use case complemented by 4 scenarios that delineated essential functional requirements for a digital calendar aimed at enhancing caregiving efficiency and support. Key features included a shared calendar system that allows multiple stakeholders to access and modify caregiving schedules through role-based access control, promoting effective communication and minimizing scheduling conflicts. Furthermore, it was proposed to incorporate advanced documentation functionalities, such as structured checklists for systematic data entry, along with automated reminders to ensure timely updates on care activities. Additional requirements encompassed task management features that facilitate task ownership and delegation, as well as contextaware features for identifying new tasks based on the care recipient's changing needs. A further focus was the integration of journaling capabilities, interactive reminders, and customizable user interfaces to enhance user experience, ensuring caregivers effectively manage their responsibilities while also prioritizing their emotional well-being.

Hence, the integration of AI-driven automation, secure data management, and ethical considerations, among others, holds the potential to create a more efficient and inclusive caregiving environment by empowering family caregivers and other key stakeholders.

In summary, the presented findings underscore the necessity of an interdisciplinary, collaborative, inclusive, and open research approach to innovate targeted and relevant Assistive Technologies for the study's target group. Through the careful investigation of real user requirements, this study has informed concrete concepts for future Assistive Technologies, laying the groundwork for user-centered outcomes.

Although the study was designed for a specific target group, it recognizes the intricate nature of the caregiving landscape and acknowledges the critical role of further stakeholders. To harmonize and fully enhance such a complex support ecosystem, the needs of these stakeholders must also be investigated. This comprehensive understanding will ensure that future ATs are effectively integrated into the broader caregiving framework, ultimately benefiting all parties involved.

## 6.2 Ethical Measures

Acknowledging the sensitive nature of caregiving roles and the criticality of the collected data, the nomination of an ethical mentor was recognized as both, essential and valuable step. This decision ensured that the study adhered to ethical standards from the outset, guiding the research in a responsible and ethically sound direction. The ethical mentorship provided by Dr. Astrid Weiss, in collaboration with the Unit of Responsible Research Practices at TU Wien, involved ongoing consultations throughout the whole study. To reflect on these efforts, the following brief summary outlines the key measures taken.

In light of the study's ethical framework, a conscious decision was made to exclude people with dementia and young carers from the research scope. This choice was driven by the understanding that working with these target groups requires specialized training and poses ethical challenges that extend beyond the scope and focus of this study.

Ensuring compliance with ethical standards, the careful validation of key documents, including interview guidelines and participant consent forms, strengthened the overall quality of the research processes.

Furthermore, to safeguard participant confidentiality, anonymization procedures were implemented for all collected data. These measures emphasize the study's commitment to maintaining data protection and privacy.

As proven to be effective, the implementation of ethical mentorship should be regarded as a fundamental component in ensuring the integrity of future research within this domain. Continuous ethical oversight and consultations, coupled with the careful selection and validation of research methods, are essential for upholding ethical standards.

In the given study, these measures reinforced the commitment to ethical practices and enhanced the overall credibility.

## 6.3 Limitations and Prospects for Future Work

The present study identified several limitations, which have been discussed in previous sections and will be briefly summarized here. Based on these identified factors, potential avenues for future research will be proposed.

Limitations experienced and identified in this research stem from three principal factors:

- 1. Complexity of the Informal Caregiving Landscape: The study acknowledges that the informal caregiving landscape is intricate and still under explored at the intersection of Assistive Technologies. Consequently, the research had to delineate its scope to focus on specific aspects of this multifaceted issue.
- 2. Access to Focus Group and Study Participants: The sensitive nature of the caregiving role, along with the associated personal data, presents significant challenges in fully engaging family caregivers. Additionally, their diverse commitments balancing professional obligations with caregiving duties often restrict their availability to participate in research activities.
- 3. Limited Availability of Assistive Technologies for Family Caregivers: The landscape of Assistive Technologies for family caregivers in Austria is notably constrained. Most existing solutions are in early development phases or pilot projects, leading to a significant lack of user feedback and validation.[SMS13][PEHR21] Notably, during the interviews, only one participant reported using an Assistive Technology, namely *Alles Clara*, highlighting the scarcity of resources. This limitation complicates the collection of comprehensive insights from caregivers, as their exposure to available ATs is minimal. Consequently, thorough requirements engineering is essential as a foundational step before developing final technological solutions, ensuring that the specific needs and challenges of caregivers are adequately addressed.

Despite these challenges, study participants exhibited a noteworthy level of openness, engagement, and motivation, which facilitated the generation of qualitative outcomes.

While the number of interviewed participants was significant for this exploratory phase, it does not fully represent the broader population within the Austrian region. However, the study identified common themes that point to underlying issues faced by caregivers, suggesting relevance for future investigation. This preliminary exploration indicates a potential for addressing these challenges in subsequent research endeavors.

#### 6.3.1 Concrete Suggestions based on Study Outcomes

On a final note, this section presents concrete suggestions derived from the findings of the present study, emphasizing key considerations that might inspire or guide future research in Assistive Technologies for family caregivers of people with dementia. Thus, the following points are proposed for consideration:

# • Importance of Qualitative Research within the Field of Assistive Technologies

As the name of ATs suggests, technologies that assist a specific target group must fully comply with user requirements to effectively provide support. Therefore, embedding qualitative research methods, especially in early design phases where fundamental requirements are explored, plays a central role.

• Understanding the Caregiving Landscape and Its Research Relevance Recognizing the complexity and sensitive nature of the informal caregiving landscape, which remains largely under-explored in the context of Assistive Technologies, should be a central focus in future research, especially given the rising number of dementia and consequently, the increasing demand for caregivers.

#### • Development of Further Assistive Technologies

The study revealed numerous directions for the development of potential Assistive Technologies, particularly based on the workshop outcomes from the focus groups. Moreover, ATs are generally welcomed by family caregivers, providing a strong foundation for co-design research approaches.

#### • Design Thinking as an Effective Research Method

In exploring the challenges faced by family caregivers of PwD, utilizing Design Thinking workshops proved to be an effective research method due to several factors. First, family caregivers and domain experts demonstrated a high level of openness, providing a strong foundation for a co-design, solution-oriented approach. Additionally, with a properly structured guide, the insights gathered offered a valuable tool for developing functional requirements for potential Assistive Technologies.

#### • Persona Development

As an overarching design method, persona development proved to be a key driver, promoting a better understanding among research participants of the given problem and enabling the development of a shared vision. Furthermore, personas offered a way to uphold objectivity and reduce biases. By identifying with a fictive persona, participants could step beyond their individual perspectives and emotional drivers. This approach allowed for solutions tailored to a broad audience rather than to individual problems.

#### • Future Investigation of Five Dominant Problem Spaces

The study identified five pressing problem spaces introduced through the five focus groups that require further investigation, namely:

- Focus Group 1: Starter Kit for Family Caregivers
- Focus Group 2: Digital Calendar & Checklist
- Focus Group 3: Care Allowance Guide & Documentation
- Focus Group 4: Networking & Knowledge Transfer
- Focus Group 5: Backup Group: Mental Well-Being

A detailed reasoning for their research relevance can be found in Chapter 4.

# • Development of a Digital Calendar with Extended Caregiving-Relevant Functionalities

As presented in Chapter 5, the idea of an extended digital calendar was highly welcomed by the study's target group. The defined functional requirements suggest further development utilizing iterative feedback loops with the target audience and relevant stakeholders. Concrete steps for future work involve developing designs of a user interface through mock-ups. Once these concepts have been validated, technical implementations can take place to introduce first prototypes.

#### • Sensitivity to Personal Data & Ethical Design

Acknowledging that the topic involves sensitive personal data requires a high level of empathy and careful composition of the research environment. Therefore, it is imperative to balance data collection with ethical considerations of privacy and anonymity.

#### • Engagement Strategies

Developing strategies to actively involve family caregivers in the design process is essential. Fostering collaboration and enhancing the relevance of the resulting technology among the target group should be a central concern to align with user expectations in future ATs.

#### • Research Design Strategies

Being aware of the multiple responsibilities that family caregivers must master – including their professional duties, caregiving roles, and personal commitments – is essential. Recognizing this complexity and providing subsequent flexibility are crucial when scheduling and planning research activities to ensure a representative sample size.

Therefore, the aforementioned key considerations are proposed as inspirations for future research. These considerations can also be viewed as lessons learned from the current study, aimed at exploring a critical topic related to the global health issue of dementia, which will significantly impact the future of caregiving, public health, and our society as a whole.[Wor22]



# Overview of Generative AI Tools Used

#### 1. Tool Name: ChatGPT

- Version: GPT-4
- Application Area: Support in text creation and idea generation
- Example Prompt:
  - Give me a structure for a master's thesis with a technical focus.
  - Correct the following text for grammatical accuracy.
  - List the features of digital calendars.
- Usage: ChatGPT was used to create the structure of the present work, which was subsequently adapted and supplemented with additional information. It also served as general inspiration and a basis for in-depth research.

ChatGPT was used in the chapter, *State of the Art*, to obtain relevant definitions in the field, conduct targeted further research, and check whether additional potential topics should be considered to deepen the research.

In the chapter, *Use Cases and Scenarios*, ChatGPT was asked about the features of a digital calendar to cover as many relevant aspects as possible. These were used as a starting point for further elaboration.

Furthermore, ChatGPT was utilized to ensure the grammatical accuracy of the present work, as well as to handle translations (DE-EN, EN-DE).



# Übersicht verwendeter Hilfsmittel

#### 1. Tool Name: ChatGPT

- Version: GPT-4
- Einsatzgebiet: Unterstützung bei der Texterstellung und Ideengenerierung
- Beispiel-Prompt:
  - Gib mir eine Struktur für eine Masterarbeit mit technischem Schwerpunkt.
  - Korrigiere den folgenden Text aus grammatikalischer Sicht.
  - Liste Eigenschaften digitaler Kalender auf.
- Verwendung: ChatGPT wurde zur Erstellung einer Struktur der vorliegenden Arbeit verwendet, die in einem nächsten Schritt adaptiert und mit zusätzlichen Informationen ergänzt wurde. Zudem diente es als allgemeine Inspiration und Grundlage für eine vertiefende Recherche.

ChatGPT wurde im Kapitel, *State of the Art* verwendet, um relevante Definitionen in dem Bereich zu erhalten, zielgerichtet weitere Recherchen durchzuführen und zu prüfen, ob potenziell weitere inhaltliche Themen berücksichtigt werden sollten, um die Tiefe der Recherche zu erweitern.

Im Kapitel, *Use Cases and Scenarios* wurde ChatGPT nach den Eigenschaften eines digitalen Kalenders gefragt, um möglichst alle relevanten Aspekte abzudecken. Diese wurden als Ausgangspunkt für eine weitergehende Bearbeitung verwendet.

Des Weiteren, wurde ChatGPT genutzt, um die grammatikalische Korrektheit der vorliegenden Arbeit sicherzustellen, sowie Übersetzungen (DE-EN, EN-DE) zu übernehmen.



# List of Figures

The Double Diamond Model	11
Double Diamond Model - Phase 1: Discover	16
Double Diamond Model - Current Status within the Double Diamond ModelCustomized Hybrid Time Management Tool	34 50 53 56
<ul> <li>Double Diamond Model - Phase 3: Develop</li></ul>	62 66 70 72 79 82 87 91
Double Diamond Model - Phase 4: Deliver	98
Interview Invitation and Participant Recruitment - German VersionInterview Invitation and Participant Recruitment - English VersionInterview Participant Consent FormInterview Guide for Family Caregivers (Page 1)Interview Guide for Family Caregivers (Page 2)Interview Guide for Experts (Page 1)Interview Guide for Experts (Page 2)	139 140 141 142 143 144 145
Workshop Invitation - General Information (Page 1)Workshop Invitation - Agenda (Page 2)Workshop Participant Consent FormWorkshop Main Table and Community AreaTable of a Selected Focus GroupBreakfast Table DesignSelf-Service Food Court	148 149 150 151 151 151 151
	Double Diamond Model - Phase 1: Discover         Double Diamond Model - Current Status within the Double Diamond Model         Customized Hybrid Time Management Tool         Alles Clara - An Excerpt from the Care Diary         Double Diamond Model - Phase 2: Define         Double Diamond Model - Phase 3: Develop         Double Diamond Model - Phase 3: Develop         Double Diamond Model - Phase 3: Develop         Design Thinking Boxes for the Focus Groups         Developed Focus Groups including a Backup Group         Overview of Personas Developed for Focus Groups 1 to 5         Design Thinking Workshop Outcome of Focus Group 1 - Workshop Phase II.         Design Thinking Workshop Outcome of Focus Group 2 - Workshop Phase II.         Design Thinking Workshop Outcome of Focus Group 3 - Workshop Phase II.         Design Thinking Workshop Outcome of Focus Group 4 - Workshop Phase II.         Design Thinking Workshop Outcome of Focus Group 4 - Workshop Phase II.         Double Diamond Model - Phase 4: Deliver         Interview Invitation and Participant Recruitment - German Version         Interview Invitation and Participant Recruitment - English Version         Interview Guide for Family Caregivers (Page 1)         Interview Guide for Family Caregivers (Page 2)         Interview Guide for Experts (Page 1)         Interview Guide for Experts (Page 2)         Workshop Invitation - General Informa

15	Persona Description of Focus Group 1 (Page 1)	153			
16	Task Description of Focus Group 1 - Workshop Phase I. (Page 2)				
17	Task Description of Focus Group 1 - Workshop Phase II. (Page 3)	155			
18	Supporting Material for Focus Group 1 - Health Care Proxy and Adult				
	Guardianship - Legal Requirements by the Austrian Government (summarized				
	by WKO)	156			
19	DT Workshop Phase I Focus Group 1	157			
20	DT Workshop Phase II Focus Group 1	157			
21	DT Workshop Final Presentation - Focus Group 1				
22	Persona and Task Description of Focus Group 2 - Workshop Phase I. (Page 1)	159			
23	Task Description of Focus Group 2 - Workshop Phase II. (Page 2)	160			
24	Supporting Material for Focus Group 2 - Daily Planner	161			
25	Supporting Material for Focus Group 2 - Role-Based Weekly Planner with				
	Color Coding	162			
26	Supporting Material for Focus Group 2 - Monthly Planner	163			
27	DT Workshop Phase I Focus Group 2	164			
28	DT Workshop Phase II Focus Group 2	164			
29	DT Workshop Final Presentation - Focus Group 2	164			
30	Persona and Task Description of Focus Group 3 - Workshop Phase I. (Page 1)	165			
31	Task Description of Focus Group 3 - Workshop Phase II. (Page 2)	166			
32	Supporting Material for Focus Group 3 - Care Allowance Amount Provided				
	by the Austrian Government)	167			
33	Supporting Material for Focus Group 3 - Guideline Template	168			
34	DT Workshop Phase I Focus Group 3	169			
35	DT Workshop Phase II Focus Group 3	169			
36	DT Workshop Final Presentation - Focus Group 3	169			
37	Persona Description of Focus Group 4 (Page 1)	170			
38	Task Description of Focus Group 4 - Workshop Phase I. (Page 2)	171			
39	Task Description of Focus Group 4 - Workshop Phase I. cont. (Page 3) .	172			
40	Task Description of Focus Group 4 - Workshop Phase II. (Page 4)	173			
41	Supporting Material for Focus Group 4 - Network Template	174			
42	DT Workshop Phase I Focus Group 4	175			
43	DT Workshop Phase II Focus Group 4	175			
44	DT Workshop Final Presentation - Focus Group 4	175			
45	Persona Description of Focus Group 5 (Page 1) $\overline{}$	176			
46	Task Description of Focus Group 5 - Workshop Phase I. (Page 2)	177			
47	Task Description of Focus Group 5 - Workshop Phase II. (Page 3)	178			

# List of Tables

3.1	Expert Interviews in Overview	40
3.2	Interviews with Family Caregivers (FC) of PwD in Overview	41
4.1	Focus Groups and Roles: Participant Composition and Expertise	77



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	135



# **Appendix A: Interview Material**

The forthcoming chapter offers a comprehensive overview of the interview materials used, supplementing those previously presented. Given the sensitive nature of the information, interview data that could be linked in any manner to study participants was anonymized to maintain confidentiality and adhere to participant consent agreements. Figures not explicitly referenced were created by the author.

# A.1: Official Interview Invitation and Participant Recruitment

The following document constitutes the official interview invitation, specifically adapted for Fonds Soziales Wien for participant recruitment. This invitation flyer, derived from an original template tailored for different stakeholder parties, has been reviewed and approved by the ethical mentorship team at TU Wien to ensure inclusive and precise wording in both German and English.





📚 Studienteilnehmer\_innen gesucht/ Study Participants Wanted (English Version below)📚

Liebes Team des Fonds Soziales Wien,

mein Name ist Viktoria Schweitzer und im Rahmen meiner Diplomarbeit zu assistiven Technologien sowie einer möglichen wissenschaftlichen Publikation an der TU Wien suche ich derzeit pflegende Angehörige von Demenzerkrankten für ein Interview (geschätzte Dauer 30 Minuten bis max. 1 Std.) und/oder eine Teilnahme an einem Workshop.

### Printergrund:

Die Pflege von Personen mit Demenzerkrankung durch Angehörige zu Hause betrifft eine wachsende Anzahl von Menschen, insbesondere angesichts der aktuellen Schätzungen, wonach in Österreich 115.000 bis 130.000 Menschen mit einer Form der Demenz leben. Dieser Bedarf wird sich aufgrund des kontinuierlichen Altersanstiegs in der Bevölkerung bis zum Jahr 2050 verdoppeln, was eine bedeutende Herausforderung in der Betreuung und Pflege darstellt.

Aus diesem Grund haben verschiedene Einrichtungen und Institutionen in Österreich Forschungsprojekte ins Leben gerufen, darunter auch die TU Wien, um die aktuelle Situation durch technologische Lösungen zu verbessern.

Wann qualifizieren Sie sich für die Studie?

Wenn Sie regelmäßig Pflegetätigkeiten für eine\_n Angehörige\_n mit Demenzerkrankung in Ihrem direkten Umfeld übernehmen.

📌 Wenn Sie in Österreich leben und die zu pflegende Person ebenfalls in Österreich lebt.

✤ Wenn Sie daran interessiert sind, positive Veränderungen durch technologische Lösungen zu bewirken, die auf den Stimmen von direkt Betroffenen basieren, dann sind Sie hier genau richtig.

Bei Interesse melde dich gerne bei mir (viktoria.schweitzer@outlook.com), und ich sende dir weitere Informationen zu.

Die Studiendaten werden gewissenhaft behandelt und bei Veröffentlichungen sorgfältig anonymisiert, um die Privatsphäre zu schützen.

Vielen Dank für Ihre Unterstützung und auf ein baldiges Kennenlernen freue ich mich, Viktoria

Kontakt/ Contact:

Viktoria Schweitzer Media and Human-Centered Computing Studentin | TU Wien Email: viktoria.schweitzer@outlook.com

View My Profile

Quellen/ Sources: https://www.sozialministerium.at/Themen/Gesundheit/Nicht-uebertragbare-Krankheiten/Demenz/Österreichischer-Demenzbericht.html https://www.sozialversicherung.at/cdscontent/load?contentid=10008.763154

Figure 1: Interview Invitation and Participant Recruitment - German Version Source: Created by Author





Study Participants Wanted

Dear Team of Fonds Soziales Wien,

My name is Viktoria Schweitzer and as part of a diploma thesis on assistive technologies and a potential scientific publication at TU Wien, I am currently seeking family caregivers of individuals with dementia for an interview (estimated duration 30 min. to max. 1 hr.) and/or participation in a workshop.

## Background:

Caring for individuals with dementia at home by family members affects a growing number of people, especially considering current estimates indicating that 115,000 to 130,000 individuals in Austria live with some form of dementia. This demand is projected to double by 2050 due to the continuous aging of the population, presenting a significant challenge in caregiving.

For this reason, various institutions and organizations in Austria have initiated research projects, including TU Wien, to improve the current situation through technological solutions.

When do you qualify for the study?

If you regularly provide care for a family member with dementia in your immediate environment.

rightarrian stream and the individual you care for also resides in Austria.

If you are interested in contributing to positive change through technological solutions based on the voices of those directly affected, then you are in the right place.

is If you are interested, please contact me (viktoria.schweitzer@outlook.com) so that I can provide you with further information.

**a** The study data is handled with diligence, and in publications, it is carefully anonymized to protect privacy.

Thank you for your support, and I look forward to meeting you soon, Viktoria

Kontakt/ Contact: Viktoria Schweitzer Media and Human-Centered Computing Studentin | TU Wien Email: viktoria.schweitzer@outlook.com

in View My Profile

Sources:

https://www.sozialministerium.at/Themen/Gesundheit/Nicht-uebertragbare-Krankheiten/Demenz/Österreichischer-Demenzbericht.html https://www.sozialversicherung.at/cdscontent/load?contentid=10008.763154

Figure 2: Interview Invitation and Participant Recruitment - English Version Source: Created by Author



# A.2: Interview Participant Consent Form



Viktoria Schweitzer viktoria.schweitzer@student.tuwien.ac.at +43 681 20500 984

# Interview Teilnehmer-Einverständniserklärung

## Zweck der Studie:

Ziel dieser Studie ist es, Informationen über die Integration von Technologie für pflegende Angehörige von Menschen mit Demenz zu sammeln. Die gesammelten Informationen werden für die Fertigstellung der Masterarbeit von Viktoria Schweitzer verwendet, Vollzeit-Masterstudentin an der Technischen Universität Wien im Studiengang, Media and Human-Centered Computing.

Persönliche Angaben des Teilnehmers:

Name	
Adresse	
Land	
Telefon	
E-mail	

## Anmerkungen:

Datum

Sollten Sie Bedenken bezüglich der Art oder Durchführung dieser Studie haben, so können Sie sich an den Leiter der Studie, Assistant Prof. Dr. in phil. Mag.a phil. Astrid Weiss. Sie können sie über die folgende Adresse kontaktieren: astrid.weiss@tuwien.ac.at.

Stellungnah	me des	Teilneh	mers:
-------------	--------	---------	-------

Ich habe das beiliegende Informationsblatt zu dieser Studie gelesen und zur Kenntnis genommen und erkläre mich mit der Teilnahme an der Studie einverstanden.	JA 🗆	NEIN 🗆
Ich bin damit einverstanden, dass das Interview mit einem Tonaufnahmegerät aufgezeichnet wird.	JA 🗆	NEIN 🗆
Ich bin damit einverstanden, dass während des Interviews Videoaufnahmen und digitale Bilder von mir gemacht werden.	JA 🗆	NEIN 🛛
Ich bin damit einverstanden, dass die Fotos und Videos für wissenschaftliche Veröffentlichungen verwendet werden.	JA 🗆	NEIN 🗆
Ich möchte kontaktiert werden, wenn ein Foto meiner Person veröffentlicht werden soll.	JA 🗆	NEIN 🗆

Figure 3: Interview Participant Consent Form Source: Created by Author

Unterschrift

# A.3: Interview Guide

# A.3.1: Interview Guide for Family Caregivers

# Interviewleitfaden – Fokusgruppe

Thema: Unterstützung für pflegende Angehörige von Personen mit Demenzerkrankungen: Rolle, Integration und Potenzial von Technologie

Interviewpartner\_in: ... Kontaktinformationen: ... Hilfreiche Links: ... Notizen: ...

Interviewdetails: Interviewdatum: ... Struktur: Strukturierte Interviews Interviewsprache: Deutsch

## Interviewstruktur

## 1. Einführung

- Danksagung: Dank an den Studienteilnehmer\_in für die Annahme des Interviews.
- Vorstellung: Kurze Vorstellung und Erläuterung des Interviewzwecks.
- Formalitäten: Bestätigung des ausgefüllten Einverständniserklärungsformulars.
- Aufzeichnung: Zustimmung zur Aufzeichnung des Interviews einholen.

## 2. Einführung und Hintergrund

- Können Sie sich bitte kurz vorstellen und Ihre Erfahrungen im Bereich der Pflege von Personen mit Demenz schildern?
- Was hat Sie dazu motiviert, an diesem Interview teilzunehmen?
- Was arbeiten Sie aktuell und wie ist die Zeitverteilung zwischen Privatleben, Job und der Pflege?
- 3. Situation und Herausforderungen
  - Wie gestaltet sich Ihr Alltag als pflegender Angehöriger? Können Sie einen typischen Tag oder eine Woche beschreiben?
  - Können Sie mir etwas über die Verteilung der Pflegeaufgaben in Ihrer Situation erzählen?
  - Welche Schwierigkeiten und Herausforderungen erleben Sie im Pflegealltag?

## 4. Brücke zwischen pflegenden Angehörigen und Pflegepersonal

- $\circ$   $\;$  Welche Herausforderungen sehen Sie in der Kommunikation und Zusammenarbeit
- zwischen pflegenden Angehörigen und professionellem Pflegepersonal?
- $\circ \quad {\rm K\"onnen Sie Beispiele für Herausforderungen oder Missverständnisse zwischen pflegenden}$
- Angehörigen und Pflegepersonal aus Ihrer Erfahrung nennen?
- 5. Verbesserungspotenziale und Bedarf
  - Wo sehen Sie Potenziale zur Verbesserung des aktuellen Pflegesystems f
    ür Menschen mit Demenz und deren Angeh
    örige?
  - Welche spezifischen Unterstützungsbedarfe haben Sie, und wo sehen Sie den größten Bedarf?

# Figure 4: Interview Guide for Family Caregivers (Page 1) Source: Created by Author

## 6. Erfahrungen mit Technologie

- Setzen Sie bereits Technologie im Rahmen der Pflege ein? Wenn ja, welche Technologien nutzen Sie?
- Welche Erfahrungen haben Sie mit bestehenden technologischen Lösungen gemacht?
- Welche Funktionen oder Möglichkeiten sollten technologische Lösungen unterstützen?

## 7. Kontinuität in der Pflege

- Wie könnte Technologie Ihrer Meinung nach zur Sicherstellung der Kontinuität in der Pflege von Menschen mit Demenz beitragen, insbesondere wenn verschiedene Akteure involviert sind?
- 8. Ethik und Datenschutz
  - Inwiefern sollten ethische Überlegungen und Datenschutzaspekte bei der Entwicklung und Anwendung von Technologien f
    ür pflegende Angeh
    örige ber
    ücksichtigt werden?

## 9. Ressourcen für pflegende Angehörige

 Wie könnten Technologien den Zugang zu Ressourcen für pflegende Angehörige erleichtern, sei es durch Informationsvermittlung, Unterstützung oder Entlastung? (z. B. durch die Vereinfachung von Prozessen wie der Beantragung professioneller Pflege oder Fördergelder)

## 10. Zusammenarbeit zwischen Forschung und Praxis

- Wie wichtig erachten Sie die interdisziplinäre Zusammenarbeit und die aktive Einbeziehung von pflegenden Angehörigen, Technologieexperten und Pflegepersonal bei der Entwicklung effektiver technologischer Lösungen?
- Glauben Sie, dass Pilotprojekte oder Workshops eine geeignete Methode darstellen, um
- diese Zusammenarbeit zu fördern und die Bedürfnisse aller Beteiligten zu berücksichtigen? 11. Feedbackmechanismen

- Wären Sie interessiert, an einem Workshop teilzunehmen, um Ihre Ideen und Bedürfnisse hinsichtlich technologischer Lösungen für pflegende Angehörige zu diskutieren und weiterzuentwickeln?
- Wie könnte kontinuierliches Feedback von pflegenden Angehörigen und Pflegepersonal in den Entwicklungsprozess von technologischen Lösungen integriert werden? Wären Sie bereit, regelmäßig Feedback zu geben, um sicherzustellen, dass die entwickelten Technologien Ihren Bedürfnissen entsprechen?

## 12. Ausblick und Weiterentwicklung

- Welche Pläne haben Sie f
  ür die Zukunft in Bezug auf Pflege und die Integration von Technologie?
- Wie wichtig halten Sie die Integration von Technologie in die Pflegepraxis f
  ür Menschen mit Demenz und deren Angeh
  örige?
- Haben Sie Empfehlungen oder Schlussgedanken zur zuk
  ünftigen Entwicklung von Technologien in diesem Bereich?

## 13. Abschluss

- Vielen Dank f
  ür Ihre Zeit und Ihre Offenheit bei diesem Interview. Gibt es noch etwas, das Sie abschließend mitteilen m
  öchten?
- Wie kann ich Sie am besten erreichen, sollten sich weitere Fragen ergeben?

Figure 5: Interview Guide for Family Caregivers (Page 2) Source: Created by Author

# A.3.2: Interview Guide for Experts

# Interviewleitfaden - ExpertInnen

Thema: Unterstützung für pflegende Angehörige von Personen mit Demenzerkrankungen: Rolle, Integration und Potenzial von Technologie

Interviewpartner\_in: ... Kontaktinformationen: ... Hilfreiche Links: ... Notizen: ...

Interviewdetails: Interviewdatum: ... Struktur: Strukturierte Interviews Interviewsprache: Deutsch

## Interviewstruktur

## 1. Einführung

- Danksagung: Dank an den Interviewpartner\_in für die Annahme des Interviews.
- Vorstellung: Kurze Vorstellung und Erläuterung des Interviewzwecks.
- Formalitäten: Bestätigung des ausgefüllten Einverständniserklärungsformulars.
- Aufzeichnung: Zustimmung zur Aufzeichnung des Interviews einholen.
- 2. Vorstellung und Hintergrund
  - Können Sie sich bitte kurz vorstellen und Ihren beruflichen Hintergrund im Bereich der Pflege und Betreuung von Personen mit Demenz erläutern?
  - Was hat Sie motiviert, an diesem Interview teilzunehmen?
  - $\circ$   $\$  Was ist Ihre derzeitige berufliche Tätigkeit, und wie beziehen sich Ihre Aufgaben auf die
  - Unterstützung pflegender Angehöriger?
- 3. Expertenbezogene Fragen
  - Frage 3.1, usw. ...
- 4. Persönliches Engagement/ Anliegen/ Motto
  - Haben Sie ein persönliches Anliegen oder Motto im Bereich der Pflege und Unterstützung von Angehörigen?
- 5. Brücke zwischen pflegenden Angehörigen und Pflegepersonal
  - Welche Hindernisse sehen Sie in der Kommunikation und Zusammenarbeit zwischen pflegenden Angehörigen und professionellem Pflegepersonal?
  - Wie könnten Technologien dazu beitragen, diese Brücke zu stärken?
- 6. Technologieunterstützung
  - Welche Technologien könnten pflegende Angehörige in ihrer täglichen Betreuungsarbeit unterstützen?
  - Gibt es bereits erfolgreiche Beispiele oder Pilotprojekte, die Sie hervorheben möchten?
  - Wie könnte die Akzeptanz von Technologien bei pflegenden Angehörigen verbessert werden?

Figure 6: Interview Guide for Experts (Page 1) Source: Created by Author

- Welche Herausforderungen sehen Sie bei der Implementierung von Technologien zur Unterstützung von pflegenden Angehörigen und Pflegepersonal?
- Können Sie konkrete Erfahrungen teilen, in denen Technologien erfolgreich zur Unterstützung von pflegenden Angehörigen eingesetzt wurden?
- Welche Entwicklungen im Bereich der Technologie könnten in Zukunft besonders relevant für die Pflege von Menschen mit Demenz sein?

## 7. Ethik und Datenschutz

- Inwiefern sollten ethische Überlegungen und Datenschutzaspekte bei der Entwicklung und Anwendung von Technologien in der Pflege berücksichtigt werden?
- 8. Ressourcen für pflegende Angehörige
  - Wie könnten Technologien den Zugang zu Ressourcen für pflegende Angehörige erleichtern, sei es durch Informationsvermittlung, Unterstützung oder Entlastung? (z. B. durch die Vereinfachung von Prozessen wie der Beantragung professioneller Pflege oder Fördergelder)
  - Wie könnte die Vernetzung von Unterstützungsangeboten, einschließlich Technologien, optimiert werden, um ein umfassendes Netzwerk für pflegende Angehörige zu schaffen?
- 9. Kontinuität in der Pflege
  - Wie könnte Technologie dazu beitragen, die Kontinuität in der Pflege von Menschen mit Demenz sicherzustellen, insbesondere wenn verschiedene Akteure beteiligt sind?
- 10. Zusammenarbeit zwischen Forschung und Praxis
  - Wie kann die Zusammenarbeit zwischen Forschungseinrichtungen und Praxisorganisationen verbessert werden, um praxisnahe Lösungen zu entwickeln?
- 11. Feedbackmechanismen
  - Wie kann kontinuierliches Feedback von pflegenden Angehörigen und Pflegepersonal in den Entwicklungsprozess von technologischen Lösungen integriert werden?
  - Würde Ihrer Meinung nach ein Design Thinking Workshop geeignet sein, um diese Zusammenarbeit zu fördern?
- 12. Interdisziplinäre Zusammenarbeit
  - Wie wichtig ist die interdisziplinäre Zusammenarbeit zwischen Technologieexperten, Pflegepersonal und Angehörigen bei der Entwicklung von Technologielösungen?
- 13. Best Practices in anderen Ländern
  - Gibt es L\u00e4nder Organisationen, die bereits ein gut etabliertes Angebot f\u00fcr pflegende Angeh\u00f6rige haben, das in \u00f6sterreich adaptiert werden k\u00f6nnte?
- 14. Bildung und Sensibilisierung
  - Wie könnten Bildungsprogramme und Sensibilisierungskampagnen dazu beitragen, das Bewusstsein für die Bedürfnisse von pflegenden Angehörigen zu schärfen?
- 15. Langfristige Perspektiven
  - Wie sehen Sie die langfristige Perspektive der Integration von Technologie in die Pflege von Menschen mit Demenz und die Unterstützung ihrer Angehörigen?
- 16. Abschluss
  - Vielen Dank f
    ür Ihre Zeit und Ihre Offenheit bei diesem Interview. Gibt es noch etwas, das Sie abschließend mitteilen m
    öchten?
  - Wie kann ich Sie am besten erreichen, sollten sich weitere Fragen ergeben?

Figure 7: Interview Guide for Experts (Page 2) Source: Created by Author



# **Appendix B: Workshop Material**

The forthcoming chapter provides a comprehensive overview of the workshop materials utilized, in addition to those previously presented. The photographs included were taken during the workshop with a personal cellphone; figures not explicitly referenced were created by the author. Consent was obtained from participants, and the consent forms are securely stored and anonymized due to the sensitive nature of the information.

# B.1: Official Workshop Invitation with Agenda



# AGESTADA BLAUF IM ÜBERBLICK: 09: 00 - 09: 30 CEMEINSAMES FRÜHSTÜCK & KENNENLERNEN 09: 30 - 10: 00

2024

APR

2 3

09:00 -	09:30	KENNENLERNEN
09:30 -	10:00	EINFÜHRUNG & ZUTEILUNG IN DIE FOKUSGRUPPEN
10:00 -	12:00	WORKSHOP TEIL I. & ARBEITEN IN FOKUSGRUPPEN
12:00 -	13:00	GEMEINSAMES MITTAGESSEN
13:00 -	14:30	WORKSHOP TEIL II. & FINALISIERUNG DER ERGEBNISSE
14:30 -	15:00	COFFEE TALK: ABSCHLIESSENDE DISKUSSIONSRUNDE PRÄSENTATION DER ERGEBNISSE

# FREUE MICH AUF DEN GEMEINSAMEN WORKSHOP!

+43 681 20 500 984 viktoria.schweitzer@outlook.com

Figure 9: Workshop Invitation - Agenda (Page 2) Source: Created by Author

# **B.2:** Workshop Participant Consent Form



Viktoria Schweitzer viktoria.schweitzer@student.tuwien.ac.at +43 681 20500 984

# Workshop Teilnehmer-Einverständniserklärung

## Zweck der Studie:

Ziel dieser Studie ist es, Informationen über die Integration von Technologie für pflegende Angehörige von Menschen mit Demenz zu sammeln. Die gesammelten Informationen werden für die Fertigstellung der Masterarbeit von Viktoria Schweitzer verwendet, Vollzeit-Masterstudentin an der Technischen Universität Wien im Studiengang, Media and Human-Centered Computing.

## Persönliche Angaben des Teilnehmers:

Name	
Adresse	
PLZ/ Land	
Telefon	
E-mail	

## Anmerkungen:

Sollten Sie Bedenken hinsichtlich der Art oder Durchführung dieser Studie haben, wenden Sie sich bitte an die Studienleiterin, Assistant Prof. Dr. phil. Mag. phil. Astrid Weiss. Sie können sie unter der folgenden E-Mail-Adresse kontaktieren: astrid.weiss@tuwien.ac.at.

## Stellungnahme des Teilnehmers:

Ich habe das beiliegende Informationsblatt zu dieser Studie gelesen und zur Kenntnis genommen und erkläre mich mit der Teilnahme an der Studie einverstanden.	JA 🗆	NEIN 🛛
Ich bin damit einverstanden, dass während des Workshops Videoaufnahmen und digitale Bilder von mir gemacht werden.	JA 🗆	NEIN 🗆
Ich bin damit einverstanden, dass die Fotos und Videos für wissenschaftliche Veröffentlichungen verwendet werden.	JA 🗆	NEIN 🛛
Ich möchte kontaktiert werden, wenn ein Foto meiner Person veröffentlicht werden soll.	JA 🗆	NEIN 🗆

Datum

Figure 10: Workshop Participant Consent Form Source: Created by Author

Unterschrift

# B.3: Workshop Location, Setup, and Design - Fostering Cohesion and Networking Among Participants



Figure 11: Workshop Main Table and Community Area



Figure 12: Table of a Selected Focus Group



Figure 13: Breakfast Table Design



Figure 14: Self-Service Food Court

# **B.4:** Comprehensive Workshop Materials by Focus Group

The following section provides a systematic overview of the materials utilized in the workshop, organized by focus group. Each subsection presents a comprehensive compilation of all materials distributed to participants during the respective focus group session. In the focus group materials, the icons representing personas were sourced from IconScout[Ico24].

# B.4.1: Focus Group 1 - Starter Package for Family Caregivers

The present section details the materials prepared for Focus Group 1 for the half-day Design Thinking workshop.

# B.4.1.1: Persona and Task Description for Focus Group 1

The present document specifies the tasks that Focus Group 1 was assigned to address during the half-day Design Thinking workshop, including a persona description.

## Fokusgruppe 1: Starterpaket für pflegende Angehörige

Persona:

- *Name:* Anna
- Alter: 35 Jahre
- **Beziehung:** Anna hat kürzlich die medizinische Diagnose der Demenz ihres Vaters erhalten. Sie ist die primäre familiäre Betreuungsperson und erwägt, die Verantwortung für die Pflege und rechtlichen Angelegenheiten ihres Vaters auf offiziellem Wege zu übernehmen, ist sich jedoch unsicher über die ethische Richtigkeit und den angemessenen Umgang.
- *Derzeitige Situation:* Die Demenz ihres Vaters befindet sich im Frühstadium, daher sind rechtliche Rahmenbedingungen noch anwendbar.

Figure 15: Persona Description of Focus Group 1 (Page 1)

## Fokusgruppe 1: Starterpaket für pflegende Angehörige

## Workshop Phase 1:

• *Frage 1:* Was hätte euch am Anfang geholfen, mit der Diagnose eures Familienmitglieds umzugehen und Pflege effektiv zu leisten?

Was hätte am Anfang geholfen, effizient durch die Herausforderungen zu navigieren und sich mit der Krankheit und verwandten Themen sensibilisiert zu fühlen?

- Aufgabe 1: Reflexion über persönliche Erfahrungen und Identifizierung von konkreten Bedürfnissen oder Unterstützungsmöglichkeiten, die euch geholfen hätten. Brainstorming von mindestens 3 konkreten Punkten, die euch geholfen hätten - bitte auf Haftnotizen festhalten.
- *Frage 2:* Welche Unterstützungsangebote stehen pflegenden Angehörigen am Anfang zur Verfügung? Wo könnt ihr euch am besten über mögliche Ressourcen informieren?
  - *Aufgabe 2:* Identifizierung und Dokumentation von verfügbaren Unterstützungsangebote und Informationsquellen. Brainstorming von mindestens 3 konkreten Punkten, die euch geholfen hätten bitte auf Haftnotizen festhalten.
- *Frage 3:* Was sind die aktuellen Herausforderungen, mit denen pflegende Angehörige bei der Navigation durch die rechtlichen und administrativen Aspekte in Österreich konfrontiert sind? *Unterfrage A:* Welche Ressourcen und Unterstützungssysteme stehen pflegenden Angehörigen in Bezug auf die Erwachsenenvertretung zur Verfügung, und wie effektiv sind sie? Wie kann der Prozess der Erlangung der Erwachsenenvertretung für pflegende Angehörige vereinfacht und zugänglicher gemacht werden?

*Unterfrage B:* Glaubt ihr, dass es mit einem sensibilisierenden Informationsmaterial beim Eintritt in den Ruhestand kombiniert werden könnte?

- Aufgabe 3: Bewertung der Effektivität vorhandener Ressourcen und Erarbeitung von Vorschlägen zur Verbesserung oder Kombination mit sensibilisierenden Materialien für den Eintritt in den Ruhestand. Identifizierung spezifischer Herausforderungen und Entwicklung von Lösungsansätzen zur Vereinfachung des Erwachsenenvertretungsprozesses, sofern nötig.
- *Frage 4*: Was wären die Top 3 Ratschläge, die ihr anderen Personen geben würdet, die sich neu in der Rolle als pflegende Angehörige befinden? Basierend auf euren eigenen Erfahrungen, was hätte euch geholfen?
  - Aufgabe 4: Formulierung von 3 konkreten Ratschlägen und Empfehlungen f
    ür angehende pflegende Angeh
    örige.
- *Frage 5:* Wärt ihr daran interessiert, Zugang zu Schulungen oder Workshops zu erhalten, um mehr über die Krankheit selbst und den Umgang mit Menschen mit Demenz sowie die Bewältigung der Herausforderungen als pflegende Angehörige zu erfahren?
  - *Aufgabe 5:* Bewertung des Bedarfs an Schulungen oder Workshops und Identifizierung der gewünschten Inhalte oder Themen.

Figure 16: Task Description of Focus Group 1 - Workshop Phase I. (Page 2)

## Fokusgruppe 1: Starterpaket für pflegende Angehörige

## Workshop Phase 2:

- Erstellt ein Starterpaket f
  ür Anna (bzw. pflegende Angeh
  örige) im Anfangsstadium der Pflege eines Familienmitglieds mit Demenz. Konzentriert euch auf konkrete Ma
  ßnahmen oder Ressourcen und priorisiert sie gegebenenfalls.
  - Identifiziert spezifische Problempunkte und Hindernisse im Erwachsenenvertretungsprozess.
  - Brainstormt Ideen zur Vereinfachung der rechtlichen und administrativen Verfahren.
  - Diskutiert mögliche Verbesserungen bestehender Unterstützungsleistungen und Ressourcen.
  - Generiert Ideen für Bildungsmaterialien oder Workshops, um pflegenden Angehörigen zu helfen.
  - Verwendet dafür das Flipchart und alle euch hilfreichen Werkzeuge sowie zusätzliches Material, das euch sinnvoll erscheint, seid kreativ:
    - Haftnotizen und Marker
    - Prozessmapping- oder Mind-Mapping-Vorlagen
    - Vorlagen f
      ür Checklisten oder Leitf
      äden
    - Zugang zu Online-Ressourcen/ Auflistung von relevanten Webseiten
    - Expertenmeinungen oder Erfahrungen von Personen, die bereits in ähnlichen Situationen waren

Figure 17: Task Description of Focus Group 1 - Workshop Phase II. (Page 3)

## **B.4.1.2:** Supporting Material for Focus Group 1

The following documents contain supplementary materials distributed during the workshop for Focus Group 1 to foster ideation and creativity, in addition to the task description presented in the previous section.

## Erwachsenenvertretungsrecht

Das Erwachsenenvertretungsrecht löste mit 1.7.2018 das bis dahin geltende Sachwalterschaftsrecht ab. Durch ein Vier-Säuten-Modell soll volljährigen Personen, die nicht (mehr) in der Lage sind, ihre Angelegenheiten selbst wahrzunehmen, mehr Selbstbestimmung zukommen: Je mehr Unterstützung benötigt wird, desto formeller ist die Vertretung.

Die vier Säulen der Erwachsenenvertretung sind:

1.	Säule: Vorsorgevollmacht
2.	Säule: gewählte Erwachsenenvertretung
2	Chula associations Franchessessesterter

4. Säule: gerichtliche Erwachsenenvertretung

## Ein erster Überblick

Vorsorgevollmacht	Vertrag zwischen Vollmachtgeber und Vorsorgebevollmächtigtem	Für den Vertragsabschluss ist die volle Entscheidungs- und Geschäftsfähigkeit erforderlich	zeitlich unbefristet gerichtliche Kontrolle sehr eingeschränkt
gewählte Erwachsenenvertretung	Wahl des Erwachsenenvertreters durch den Betroffenen	Dafür ist die eingeschränkte Entscheidungs- und Geschäftsfähigkeit ausreichend	Auswahl einer nahestehenden Person als Vertreter Vertreter wird nur im Bedarfsfall tätig zeitlich unbefristet
gesetzliche Erwachsenenvertretung	nahe Angehörige sind bereit, die Vertretung zu übernehmen	keine Entscheidungs- und Geschäftsfähigkeit mehr vorhanden	Widerspruchsrecht des Betroffenen befristet auf drei Jahre
gerichtliche Erwachsenenvertretung	Auswahl des Erwachsenenvertreters durch das Gericht	keine Entscheidungs- und Geschäftsfähigkeit mehr vorhanden	befristet auf drei Jahre

Vorsorgevollmacht: Durch die Vorsorgevollmacht haben entscheidungsfähige voltjährige Personen die Möglichkeit, Vorsorge für den späteren Vertust ihrer Entscheidungsfähigkeit zu treffen. Der Voltmachtgeber kann mithilfe der Vorsorgevollmacht einen oder mehrere Vertreter bestimmen, die ihn bei Eintritt der Entscheidungsunfähigkeit in den ihm/ihnen übertragenen Angelegenheiten vertreten.

gewählte Erwachsenenvertretung: Ist die Entscheidungsfähigkeit des Betroffenen beeinträchtigt und hat er keinen Vertreter bestimmt, kann er keine Vorsorgevollmacht mehr errichten. Ist er aber noch fähig, die Bedeutung und die Folgen einer Bevollmächtigung in Grundzügen zu verstehen, kann er eine oder mehrere ihm nahestehende Personen als Erwachsenenvertreter zur Besorgung seiner Angelegenheiten auswählen.

gesetzliche Erwachsenenvertretung: Kann oder will die beschränkt entscheidungsfähige Person keinen Vertreter wählen, besteht die Möglichkeit, dass einem oder mehreren nahen Angehörigen die Vertretung des Betroffenen übertragen wird. Der Nachteil der gesetzlichen Erwachsenenvertretung besteht für den Betroffenen darin, dass er selbst keinen Einfluss auf die Wahl des Vertreters hat.

gerichtliche Erwachsenenvertretung: Kommt eine gesetzliche Erwachsenenvertretung durch einen nahen Angehörigen des Betroffenen nicht in Betracht, hat das Gericht einen Vertreter (z.B. einen Rechtsanwalt oder Notar) für den in seiner Entscheidungsfähigkeit Beeintrachtigten zu bestellen. Auch in diesem Fall kann der Betroffene nicht beeinflussen, wer vom Bericht als Vertreter bestimmt wird.

Figure 18: Supporting Material for Focus Group 1 - Health Care Proxy and Adult Guardianship - Legal Requirements by the Austrian Government (summarized by WKO) Source: [Öst23]

# B.4.1.3: Workshop Results and Tangible Outcomes of Focus Group 1

The following images capture the milestones and results of Focus Group 4 during phases I and II of the Design Thinking Workshop, including the tangible outcomes showcased in the final presentation.



Figure 19: DT Workshop Phase I. - Focus Group 1



Figure 20: DT Workshop Phase II. - Focus Group 1



Figure 21: DT Workshop Final Presentation - Focus Group 1



# B.4.2: Focus Group 2 - Digital Calendar and Checklist

The present section details the materials prepared for Focus Group 2 for the half-day Design Thinking workshop.

## B.4.2.1: Persona and Task Description for Focus Group 2

The present document specifies the tasks that Focus Group 2 was assigned to address during the half-day Design Thinking workshop, including a persona description.

## Fokusgruppe 2: Digitaler Kalender & Checkliste

Persona:

- Name: David
  Alter: 75 Jahre
- Beziehung: David ist der Ehepartner und kümmert sich um seine Frau, bei der Demenz diagnostiziert wurde. Er möchte seine Zeit optimal nutzen, um seiner Frau die bestmögliche Pflege zu bieten, während er gleichzeitig seine eigenen Verantwortlichkeiten bewältigt.



**Derzeitige Situation:** Die Demenz seiner Frau hat sich zu einem Punkt entwickelt, an dem sie rund um die Uhr Pflege benötigt. Sie wurde als Pflegestufe 3 eingestuft, wodurch David für das Pflegegeld berechtigt ist.

## Workshop Phase 1:

- Frage 1: Welche sind die Hauptprobleme, mit denen pflegende Angehörige bei der Organisation und Koordination der Pflege f
  ür ihre Angehörigen konfrontiert sind?
  - Aufgabe 1: Reflexion über persönliche Erfahrungen und Identifizierung von konkreten Herausforderungen, die die größte Hürde darstellen. Brainstorming von mindestens 3 konkreten Punkten, die eine besondere Herausforderung darstellen bitte auf Haftnotizen festhalten.
- Frage 2: Wie könnt ihr Technologie nutzen, um die Kommunikation und Koordination zwischen pflegenden Angehörigen und anderen Beteiligten zu verbessern? Nutzt ihr bereits digitale Werkzeuge wie Kalender, To-Do-Listen oder Chatgruppen wie WhatsApp? Wofür genau? Welche Funktionen sind besonders hilfreich, und wo seht ihr Verbesserungspotenzial bzw. was fehlt euch?
  - Aufgabe 2: Evaluierung der aktuellen Nutzung von digitalen Tools und Diskussion darüber, wie diese optimiert werden könnten, um die Pflegeorganisation zu verbessern.
- Frage 3: Welche Funktionen wären in einem Kalender oder Planungstool f
  ür pflegende Angeh
  örige am n
  ützlichsten?
  - Aufgabe 3: Identifizierung der gewünschten Funktionen und Priorisierung der wichtigsten Aspekte eines idealen Planungstools für die Pflegeorganisation - bitte auf Haftnotizen festhalten.
- Frage 4: Wie würde ein täglicher/ wöchentlicher/ monatlicher Kalenderplaner aussehen? Unterfrage A: Würdet ihr eine To-Do-Liste für den Tag/ Woche, sowie eine Checkliste für Aktivitäten integrieren? Welche anderen Funktionalitäten wären für euch wichtig?
  - Aufgabe 4: Kreative Ideensammlung eines Kalenders für verschiedene Zeiträume (täglicher/ wöchentlicher/ monatlicher Kalenderplaner). Brainstorming von mindestens 3 konkreten Punkten pro Ansicht - bitte auf Haftnotizen festhalten.
- Frage 5: Wärt ihr daran interessiert, einen gemeinsam nutzbaren Kalender mit einer bestimmten Benutzergruppe zu haben? Könnte es hilfreich sein, wenn professionelle Pflegekräfte, der primäre Hausarzt und andere relevante Personen darauf zugreifen könnten?
   Aufgabe 5: Bewertung des Bedarfs an geteilten Kalendern und Identifizierung, ob
  - eine individuell definierte Benutzergruppe hilfreich wäre.

Figure 22: Persona and Task Description of Focus Group 2 - Workshop Phase I. (Page 1)

## Fokusgruppe 2: Digitaler Kalender & Checkliste

## Workshop Phase 2:

 Erstellt einen fiktiven Wochenkalender mit allen relevanten Terminen von Davids Frau, um David bestmöglich den Überblick zu ermöglichen. Obwohl es sich um die Termine seiner Frau handelt, hat David aufgrund der Erkrankung Hauptzugriff. Persönliche Termine von David sollen diesmal nicht eingeplant werden.

Integriert alle relevanten Funktionen, die ihm helfen könnten, seine Familie und andere beteiligte Akteure bestmöglich zu koordinieren und die Pflege ausgewogen zu gestalten. Denkt dabei an konkrete Kalendereinträge wie Arztbesuche, Besuche von Familienmitgliedern/Freunden sowie Zeiträume, in denen Davids Frau in Tageszentren oder bei professioneller Pflege vor Ort ist.

Überlegt euch, welche Bedeutung Farben haben könnten (z. B.: eine Aktivität = eine bestimmte Farbe).

Soll eine To-Do-Liste für jeden Tag vorhanden sein (z. B.: einkaufen gehen)? Soll zusätzlich zu jeder Aktivität, z. B.: einkaufen gehen, eine Checkliste inkludiert sein (z. B.: um eine Einkaufsliste zu erfassen)?

- Als Inspiration könnt ihr die mitgelieferten Vorlagen verwenden. Stellt das Endergebnis bitte auf einem Flipchart dar. Gerne könnt ihr mehrere Ansichten erstellen, aber der Wochenkalender soll im Fokus stehen.
- Identifiziert gemeinsame Problempunkte und Ineffizienzen in den aktuellen Koordinationsmethoden der Pflege. Brainstormt Funktionalitäten für ein digitales Werkzeug, das diese Herausforderungen adressiert.
- $\circ \quad \mbox{Priorisiert gedanklich Funktionen basierend auf ihrer wahrgenommenen Nützlichkeit.}$
- Verwendet dafür das Flipchart und alle euch hilfreichen Werkzeuge sowie zusätzliches Material, das euch sinnvoll erscheint, seid kreativ:
  - Haftnotizen und Marker
  - Prozessmapping- oder Mind-Mapping-Vorlagen
  - Vorlagen f
    ür Checklisten oder Leitf
    äden
  - Zugang zu Online-Ressourcen/ Auflistung von relevanten Webseiten
  - Expertenmeinungen oder Erfahrungen von Personen, die bereits in ähnlichen Situationen waren

Figure 23: Task Description of Focus Group 2 - Workshop Phase II. (Page 2)

# B.4.2.2: Supporting Material for Focus Group 2

The following documents contain supplementary materials distributed during the workshop for Focus Group 2 to foster ideation and creativity, in addition to the task description presented in the previous section.

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12-1 PM				
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Figure 24: Supporting Material for Focus Group 2 - Daily Planner Source: [Can24a]

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Figure 25: Supporting Material for Focus Group 2 - Role-Based Weekly Planner with Color Coding

Source: [Tea24]



Figure 26: Supporting Material for Focus Group 2 - Monthly Planner Source: [Can 24b]

# B.4.2.3: Workshop Results and Tangible Outcomes of Focus Group 2

The following images capture the milestones and results of Focus Group 2 during phases I and II of the Design Thinking Workshop, including the tangible outcomes showcased in the final presentation.



Figure 27: DT Workshop Phase I. - Focus Group 2



Figure 28: DT Workshop Phase II. - Focus Group 2



Figure 29: DT Workshop Final Presentation - Focus Group 2
# B.4.3: Focus Group 3 - Care Allowance Guide and Documentation

The present section details the materials prepared for Focus Group 3 for the half-day Design Thinking workshop.

## B.4.3.1: Persona and Task Description for Focus Group 3

The present document specifies the tasks that Focus Group 3 was assigned to address during the half-day Design Thinking workshop, including a persona description.

## Fokusgruppe 3: Pflegegeld Leitfaden & Dokumentation

Persona:

- Name: Lisa
- Alter: 55 Jahre
- **Beziehung:** Lisa hat kürzlich herausgefunden, dass ihre Mutter Frühstadium-Demenz hat. Sie sucht nach Informationen darüber, wie sie finanzielle Unterstützung erhalten kann, und benötigt Anleitung zu den Schritten im Antragsprozess für das Pflegegeld.



Derzeitige Situation: Lisas Mutter wurde noch nicht f
ür das Pflegegeld eingestuft, aber Lisa
erkundet ihre Optionen, w
ährend sich der Zustand ihrer Mutter verschlechtert. Es liegt bereits
eine Diagnose der Krankheit vor.

### Workshop Phase 1:

- *Frage 1:* Welche sind die Hauptprobleme, mit denen pflegende Angehörige beim Navigieren durch das Pflegegeldsystem in Österreich konfrontiert sind?
  - Aufgabe 1: Reflektiert über persönliche Erfahrungen und identifiziert konkrete Herausforderungen, die beim Beantragen des Pflegegeldes auftreten können. Brainstorming von mindestens 3 konkreten Punkten - bitte notiert sie auf Haftnotizen.
- Frage 2: Wie können Informationen und Anleitungen zur Pflegegeldberechtigung und den Antragsverfahren für pflegende Angehörige leichter zugänglich gemacht werden?
  - Aufgabe 2: Brainstormt Ideen zur Verbesserung der Zugänglichkeit und Klarheit von Informationen zu Pflegegeldberechtigung und Antragsverfahren.
- Frage 3: Was sind die Hindernisse bei der Beantragung finanzieller Unterstützung?
   Aufgabe 3: Identifiziert Hürden und Engpässe im Antragsprozess für finanzielle Unterstützung.
- *Frage 4:* Bevorzugt ihr eine persönliche Beratung oder wäre es auch in Ordnung, eine digitale Anleitung zu haben? Möchtet ihr gerne an einem Workshop teilnehmen oder Videomaterial bekommen, das zeigt, wie das Formular ausgefüllt werden soll?
  - Aufgabe 4: Diskutiert über eure Präferenzen bezüglich der Art der Unterstützung sowie der Bereitstellung von Schulungen und Hilfestellungen, wie persönlicher Beratung, digitalen Anleitungen, Workshops oder Videomaterial.
- Frage 5: Welche zusätzliche Unterstützung oder Ressourcen wären hilfreich f
  ür pflegende Angeh
  örige im Zusammenhang mit dem Pflegegeld?
  - Aufgabe 5: Identifiziert den Bedarf an zusätzlicher Unterstützung und Ressourcen für pflegende Angehörige im Zusammenhang mit dem Pflegegeld und diskutiert mögliche Lösungen oder Verbesserungen.

Figure 30: Persona and Task Description of Focus Group 3 - Workshop Phase I. (Page 1)

## Fokusgruppe 3: Pflegegeld Leitfaden & Dokumentation

## Workshop Phase 2:

 Erstellt einen Leitfaden für Lisa, um ihr bei der Beantragung von Pflegegeld zu helfen. Strukturiert den Leitfaden am besten als Schritt-für-Schritt-Anleitung, die Lisa durch den Prozess führt. Eine mögliche Struktur könnte sich an den Pflegestufen orientieren, aber es gibt auch andere logische Möglichkeiten. Beginnt mit der Ausarbeitung für Pflegestufe 1 und behandelt bei Bedarf auch die weiteren Stufen, sofern noch Zeit bleibt.

Dabei sollen alle wichtigen Schritte zusammengefasst werden, die entweder für das Ausfüllen des Antragsformulars selbst benötigt werden oder als Vorbereitung oder Nachbereitung dienen. Berücksichtigt dabei auch konkrete Fragestellungen, die im Formular auftauchen könnten. Verwendet das offizielle Formular für den Antrag und ergänzt es um die Informationen, die für euch wichtig sind oder die ihr benötigt. Falls erforderlich oder nützlich, integriert im Wegweiser auch eine kurze Überprüfung der Eintrittskriterien (die im Formular nicht behandelt werden?). Dies soll Fälle abfangen, die den unnötigen Beantragungsprozess bereits zu Anfang identifizieren.

- o Als Inspiration könnt ihr die mitgelieferten Vorlagen verwenden.
- Identifiziert Lücken und Defizite in den aktuellen Informations- und Unterstützungsdiensten im Zusammenhang mit dem Pflegegeld.
- Brainstormt Ideen zur Verbesserung der Zugänglichkeit und Klarheit von Informationen zur Pflegegeldberechtigung und den Antragsverfahren.
- Diskutiert potenzielle Strategien zur Bereitstellung persönlicher Unterstützung und Anleitung für pflegende Angehörige, die sich im Pflegegeldsystem zurechtfinden müssen.
- Verwendet dafür das Flipchart und alle euch hilfreichen Werkzeuge sowie zusätzliches Material, das euch sinnvoll erscheint, seid kreativ:
  - Haftnotizen und Marker
  - Prozessmapping- oder Mind-Mapping-Vorlagen
  - Vorlagen f
    ür Checklisten oder Leitf
    äden
  - Zugang zu Online-Ressourcen/ Auflistung von relevanten Webseiten
  - Expertenmeinungen oder Erfahrungen von Personen, die bereits in ähnlichen Situationen waren

Figure 31: Task Description of Focus Group 3 - Workshop Phase II. (Page 2)

# B.4.3.2: Supporting Material for Focus Group 3

The following documents contain supplementary materials distributed during the workshop for Focus Group 3 to foster ideation and creativity, in addition to the task description presented in the previous section.

oesterreich.gv.at	ID Austria eAusweise Lebenslagen Themen	Services	Q A DE ~
Ĝ → Themen → Pflege → Pflegegeld → Höhe des Pflegegeldes			
Familie und Partnerschaft	Pflegebedarf in Stunden pro Monat	Pflegestufe	Betrag in Euro monatlich (netto)
Gesetze und Recht	Mehr als 65 Stunden	1	192,00 Euro
Gesundheit	Mehr als 95 Stunden	2	354,00 Euro
Hilfe leisten	Mehr als 120 Stunden	3	551,60 Euro
Hilfe und (finanzielle) Unterstützung	Mehr als 160 Stunden	4	827,10 Euro
erhalten Menschen aus anderen Staaten	Mehr als 180 Stunden, wenn • ein außergewöhnlicher Pflegeaufwand erforderlich ist	5	1.123,50 Euro
Menschen mit Behinderungen	Mehr als 180 Stunden, wenn <ul> <li>zeitlich unkoordinierbare Betreuungsmaßnahmen erforderlich sind und diese regelmäßig während des Tanse und des Nacht zu erbringen sind oder.</li> </ul>	6	1.568,90 Euro
Notfälle, Unfälle und Kriminalität	<ul> <li>die dauernde Anwesenheit einer Pflegeperson während des Tages und der Nacht erforderlich ist, weil die Wahrscheinlichkeit einer Eigen- oder Fremdgefährdung gegeben ist</li> </ul>	dich ist, glich	2.061,80 Euro
Onlinesicherheit, Internet und neue Medien			
Persönliche Dokumente und Bestätigungen	<ul> <li>Mehr als 180 Stunden, wenn</li> <li>keine zielgerichteten Bewegungen der vier Extremitäten mit funktioneller Umsetzung möglich sind oder</li> <li>ein gleich zu achtender Zustand vorliegt</li> </ul>		
Pflege			

Figure 32: Supporting Material for Focus Group 3 - Care Allowance Amount Provided by the Austrian Government)

Source: [Bun24b]

# Timeline



Figure 33: Supporting Material for Focus Group 3 - Guideline Template Source: [Sli24]

# B.4.3.3: Workshop Results and Tangible Outcomes of Focus Group 3

The following images capture the milestones and results of Focus Group 3 during phases I and II of the Design Thinking Workshop, including the tangible outcomes showcased in the final presentation.



Figure 34: DT Workshop Phase I. - Focus Group 3



Figure 35: DT Workshop Phase II. - Focus Group 3



Figure 36: DT Workshop Final Presentation - Focus Group 3

# B.4.4: Focus Group 4 - Network and Knowledge Transfer

The present section details the materials prepared for Focus Group 4 for the half-day Design Thinking workshop.

## B.4.4.1: Persona and Task Description for Focus Group 4

The present document specifies the tasks that Focus Group 4 was assigned to address during the half-day Design Thinking workshop, including a persona description.

## Fokusgruppe 4: Netzwerk & Wissenstransfer

Persona:

- *Name:* Mark
- *Alter:* 40 Jahre
- Beziehung: Seit zwei Jahren kümmert sich Mark um seinen Vater, der an Demenz leidet. In dieser Zeit hat er die Bedeutung von Unterstützung und Informationsaustausch erkannt. Um sich weniger überfordert zu fühlen, möchte er sich mit anderen pflegenden Angehörigen vernetzen, die ihm wertvolle Einsichten geben könnten.



• **Derzeitige Situation:** Marks Vater wurde als Pflegestufe 4 eingestuft, und Mark sucht zusätzliche Unterstützung und Ressourcen, um ihn in seiner Pflegerolle zu unterstützen. Da er oft nicht weiß, wie er am besten auf seinen Vater zugehen soll und allgemein wie er am besten mit der Situation umgehen soll, würde er es schätzen, echtes Feedback von Menschen in einer ähnlichen Situation zu erhalten.

Figure 37: Persona Description of Focus Group 4 (Page 1)

## Fokusgruppe 4: Netzwerk & Wissenstransfer

#### Workshop Phase 1:

- Frage 1: Was sind die Hauptprobleme, mit denen pflegende Angehörige beim Zugang zuverlässiger Informationen und Unterstützung im Zusammenhang mit der Erkrankung, Pflege, Rechten usw. konfrontiert sind?
  - Aufgabe 1: Reflektiert über persönliche Erfahrungen und identifiziert konkrete Herausforderungen, die den Zugang zuverlässiger Informationen und Unterstützung erschweren. Notiert mindestens drei Hauptprobleme auf Haftnotizen.
- Frage 2: Welche Themen oder Anliegen sollten eurer Meinung nach in einem Peer-Support-Netzwerk, einer Wissensdatenbank oder einer Hotline f
  ür Demenzpflege auf jeden Fall behandelt werden?
  - Aufgabe 2: Diskutiert in der Gruppe, welche Themen oder Anliegen in einem Peer-Support-Netzwerk, einer Wissensdatenbank oder einer Hotline für Demenzpflege unbedingt abgedeckt werden sollten, und notiert eure Ideen auf Haftnotizen.
- Frage 3: Welche Quellen/Netzwerke/Communitys gibt es in Österreich?
  - Aufgabe 3: Recherchiert in der Gruppe nach vorhandenen Quellen, Netzwerken und Communities in Österreich, die pflegenden Angehörigen Unterstützung bieten könnten. Sammelt Informationen und notiert sie auf Haftnotizen oder in einer Liste.
- *Frage 4:* Würdet ihr eher einen persönlichen Austausch (z.B.: Café Zeitreise) oder Online-Austausch (z.B.: Zoom Coffee) bevorzugen, oder sogar beides?
  - Aufgabe 4: Diskutiert in eurer Gruppe die Vor- und Nachteile eines persönlichen und eines Online-Austauschs für pflegende Angehörige. Entscheidet, welche Form des Austauschs warum bevorzugt wird, und notiert die Gründe auf Haftnotizen.
- Frage 5: Wenn ihr schnell eine Frage habt oder Unterstützung benötigt, welchen Weg bevorzugt ihr: eine Hotline anzurufen, persönliche Beratung oder eine zentralisierte Plattform, um Informationen zu finden? Warum? Oder denkt ihr, dass verschiedene Situationen unterschiedliche Lösungen erfordern? Könntet ihr euch vorstellen, ein Forum oder eine Fragen & Antworten (Q&A) -Website zu nutzen?
  - Aufgabe 5: Besprecht in eurer Gruppe die Vor- und Nachteile von Hotlines, persönlicher Beratung und zentralisierten Plattformen für schnelle Anfragen. Entscheidet gemeinsam, welche Unterstützungsform bevorzugt wird, und haltet eure Gründe auf Haftnotizen fest.
- Frage 6: Stellen wir uns vor, es gäbe die Möglichkeit, das Wissen, das ihr bereits zu bestimmten Themen rund um Demenz aufgebaut habt, mit anderen zu teilen. Als Gegenleistung erhieltet ihr eine telefonische, individuelle Beratung zu Themen, bei denen ihr Unterstützung benötigt, und das flexibel, ohne lange Wartezeiten. Je mehr Teilnehmer, desto mehr Wissen und Beratungsthemen wären im Angebot. Was denkt ihr darüber, würdet ihr an einem solchen Angebot interessiert sein? In welcher Form könnte so etwas funktionieren? Denkt dabei an die Vergütung; wäre es auf freiwilliger Basis oder mit Vergütung? Fällt euch etwas Passenderes ein? Wie würdet ihr pflegende Angehörige miteinander vernetzen?
  - Aufgabe 6: Diskutiert in eurer Gruppe die Machbarkeit und den Nutzen eines Wissensaustausch-gegen-Beratungskonzepts für pflegende Angehörige. Brainstormt Ideen zur Umsetzung und zur Vergütung. Denkt auch über alternative Ansätze nach und notiert eure Gedanken auf Haftnotizen.

Figure 38: Task Description of Focus Group 4 - Workshop Phase I. (Page 2)

## Fokusgruppe 4: Netzwerk & Wissenstransfer

• Die folgende Frage ist besonders sensibel. Bitte fühlt euch frei, diese Frage zu überspringen, wenn ihr euch damit unwohl fühlt. Als Ermutigung möchte ich allerdings betonen, dass wir hier sind, um euch zu unterstützen, und ihr habt nun die Möglichkeit, mit einer erfahrenen Expertin darüber zu sprechen. Ihr seid in sicheren Händen.

*Frage 7:* Und was passiert danach? Habt ihr schon einmal darüber nachgedacht, ob es eine Möglichkeit gibt, eine Unterstützung einzubeziehen nach dem Verlust des zu pflegenden Familienmitglieds? Wärt ihr daran interessiert, Unterstützung oder eine Begleitung in diesen schwierigen Momenten zu erhalten? Gibt es bereits bestimmte Bereiche, in denen ihr wisst, dass ihr Unterstützung gut gebrauchen könntet?

 Aufgabe 7: Diskutiert mögliche Ressourcen und Hilfsangebote, die in solchen Situationen hilfreich wären. Erörtert auch, wie ihr eine solche Unterstützung annehmen würdet und welche Bereiche für euch besonders wichtig wären.

Figure 39: Task Description of Focus Group 4 - Workshop Phase I. cont. (Page 3)

## Fokusgruppe 4: Netzwerk & Wissenstransfer

### Workshop Phase 2:

 Die Aufgabe besteht darin, Möglichkeiten zu erkunden, wie pflegende Angehörige miteinander verbunden werden können, um Mark in seiner Zielsetzung zu unterstützen. Welche Netzwerke, Communities und Hotlines gibt es bereits, und welche weiteren wünscht ihr euch? Nutzt die Erkenntnisse aus dem ersten Workshop, um eine Landkarte mit möglichen Kontaktstellen und Netzwerken zu erstellen, um den Überblick zu bewahren. Da es bereits viele gute Ouellen gibt, soll eine Gesamtübersicht nun gewährleistet werden.

Diese Landkarte dient Mark als Leitfaden, um gezielt nach Unterstützung zu suchen, die seinen individuellen Bedürfnissen entspricht. Nutzt dabei gerne die mitgelieferten Vorlagen als Inspiration, jedoch sollen eure eigenen Ideen und Konzepte auf dem Flipchart präsentiert werden.

Nutzt gerne die Fragen und Ideen aus dem vorherigen Gespräch (Workshop Teil 1) als Leitfaden. Anbei weitere Punkte zum Gedankenanstoß:

- Identifiziert Lücken und Einschränkungen in den derzeitigen Unterstützungsangeboten, insbesondere hinsichtlich der Vernetzungsmöglichkeiten und des Wissenstransfers. Entwickelt Ideen, wie Peer-Support-Netzwerke und Hotlines für pflegende Angehörige etabliert und gefördert werden können.
- Diskutiert Möglichkeiten für verschiedene Formate und Kanäle, die einen einfachen Zugriff auf Informationen und Unterstützung ermöglichen, wie zum Beispiel:
  - Online-Foren: Plattformen, auf denen pflegende Angehörige sich online austauschen können, Fragen stellen und Ratschläge erhalten.
  - Telefon-Hotlines: Rund um die Uhr erreichbare telefonische Beratungsdienste, die direkte Unterstützung bieten.
  - Persönliche Unterstützungsgruppen: Lokale Treffen oder Gruppensitzungen, bei denen sich pflegende Angehörige persönlich treffen, um ihre Erfahrungen zu teilen und Unterstützung zu erhalten.
  - Webinare und Online-Seminare: Virtuelle Veranstaltungen, die Wissen vermitteln, Tipps geben und eine interaktive Plattform f
    ür den Austausch bieten.
  - Mobile Apps: Potenzielle Anwendungen, die speziell f
    ür pflegende Angeh
    örige entwickelt werden sollen und Funktionen wie Selbsthilfegruppen, Erinnerungen f
    ür Medikamente und Stressmanagement-Tools bieten.
- Verwendet dafür das Flipchart und alle euch hilfreichen Werkzeuge sowie zusätzliches Material, das euch sinnvoll erscheint, seid kreativ:
  - o Haftnotizen und Marker
  - $\circ \quad \mbox{Prozessmapping- oder Mind-Mapping-Vorlagen}$
  - Vorlagen f
    ür Checklisten oder Leitf
    äden
  - o Zugang zu Online-Ressourcen/ Auflistung von relevanten Webseiten
  - Expertenmeinungen oder Erfahrungen von Personen, die bereits in ähnlichen Situationen waren

Figure 40: Task Description of Focus Group 4 - Workshop Phase II. (Page 4)

## **B.4.4.2:** Supporting Material for Focus Group 4

The following documents contain supplementary materials distributed during the workshop for Focus Group 4 to foster ideation and creativity, in addition to the task description presented in the previous section.



Figure 41: Supporting Material for Focus Group 4 - Network Template Source: [Gre24]

# B.4.4.3: Workshop Results and Tangible Outcomes of Focus Group 4

The following images capture the milestones and results of Focus Group 4 during phases I and II of the Design Thinking Workshop, including the tangible outcomes showcased in the final presentation.



Figure 42: DT Workshop Phase I. - Focus Group 4



Figure 43: DT Workshop Phase II. - Focus Group 4



Figure 44: DT Workshop Final Presentation - Focus Group 4

# B.4.5: (Back Up) Focus Group 5 - Mental Well-Being

The present section outlines the tasks for a potential fifth focus group, established as a backup, in case an additional group had been needed for the study's half-day Design Thinking workshop. Given the final number of participants, perceived group dynamics, and the distribution of participants' profiles (i.e., experts and family caregivers), an additional group was deemed less effective and was not utilized for the workshop. Nonetheless, this focus group remains a relevant area for future research, particularly in addressing the critical aspects and challenges highlighted in the task description.

## B.4.5.1: Persona and Task Description for Focus Group 5

The present document specifies the tasks prepared for Focus Group 5, including a persona description.

## **Backup-Fokusgruppe 5: Mentales Wohlbefinden**

## Persona:

- Name: Sarah
- Alter: 60 Jahre
- Beziehung: Sarah kümmert sich seit über sechs Jahren um ihren Ehemann, der an fortgeschrittener Demenz leidet. Sie erlebt Burnout als direkte Angehörige und sucht emotionale Unterstützung sowie Strategien zur Erhaltung ihres mentalen Wohlbefindens.



• **Derzeitige Situation:** Obwohl Sarah professionelle Unterstützung in der Pflege erhält, wird die emotionale Belastung immer gravierender, da sie doch die primäre Person ist, die in allen Angelegenheiten die Verantwortung trägt. Trotz der Möglichkeit, weitere Unterstützung zu erhalten, kann sie sich nicht vorstellen, ihren Mann in ein Pflegeheim zu geben, aus Sorge um sein Wohlergehen und ihrer engen Verbundenheit zueinander.

Figure 45: Persona Description of Focus Group 5 (Page 1)

## **Backup-Fokusgruppe 5: Mentales Wohlbefinden**

#### Workshop Phase 1:

- Frage 1: Welche sind die zentralen Herausforderungen, denen sich pflegende Angehörige in Bezug auf ihre mentale Gesundheit stellen müssen, und wie wirken sich diese auf ihr Wohlbefinden und ihre Kapazität aus, um eine effiziente und ausgewogene Pflege zu leisten?
  - Aufgabe 1: Identifiziert die Hauptprobleme, die pflegende Angehörige im Zusammenhang mit ihrer mentalen Gesundheit erfahren, und untersucht, wie sich diese Probleme auf ihre Kapazität auswirken, eine angemessene Pflege zu leisten.
- Frage 2: Welche Ressourcen und Unterstützungsdienste stehen derzeit zur Verfügung, um den Bedürfnissen der psychischen Gesundheit/ mentalem Wohlbefinden von pflegenden Angehörigen gerecht zu werden, und wie effektiv sind sie? Habt ihr persönliche Strategien oder Geheimtipps, die euch geholfen haben, eure mentale Gesundheit zu pflegen und ausgewogen zu bleiben in dieser schwierigen Situation?
  - Aufgabe 2: Diskutiert vorhandene Unterstützungsangebote, sowie mögliche Lösungsansätze, um diese Herausforderungen anzugehen. Bewertet gemeinsam die Effektivität der verfügbaren Ressourcen und Unterstützungsdienste für die psychische Gesundheit von pflegenden Angehörigen.
- Frage 3: Welche Art von Diensten und in welcher Form (persönlicher Kontakt/ Online-Unterstützung/ beides) würden am meisten dazu beitragen, die täglichen Herausforderungen in der Pflege im Hinblick auf das mentale Wohlbefinden zu bewältigen und mit der Situation umzugehen?
  - Aufgabe 3: Diskutiert die Vor- und Nachteile verschiedener Dienstleistungsformen zur Unterstützung von pflegenden Angehörigen im Bereich des mentalen Wohlbefindens und erarbeitet Empfehlungen für Dienstleistungsanbieter, um die Bedürfnisse der Pflegenden besser zu erfüllen.
- Frage 4: Gibt es Defizite bei der Inanspruchnahme von Dienstleistungen zur Förderung der mentalen Gesundheit?
  - Aufgabe 4: Identifiziert mögliche Hindernisse bei der Inanspruchnahme von Dienstleistungen zur Förderung der mentalen Gesundheit und erarbeitet Lösungsansätze zur Überwindung dieser Hindernisse.
- *Frage 5:* Welche psychologischen Auswirkungen hat die Langzeitpflege auf das Wohlbefinden, die Selbstwahrnehmung und das soziale Ansehen von pflegenden Angehörigen?
  - Aufgabe 5: Diskutiert die psychischen Belastungen, denen pflegende Angehörige ausgesetzt sind, sowie die Auswirkungen auf ihr Selbstbild und ihr soziales Ansehen. Entwickelt Ansätze, um deren Selbstwahrnehmung und mentales Wohlbefinden zu stärken und ihr soziales Ansehen zu verbessern. Überlegt, welche Maßnahmen, wie beispielsweise Werbekampagnen und Sensibilisierungsmaterialien, dazu beitragen könnten, pflegende Angehörige in der Gesellschaft besser zu repräsentieren.
- *Frage 6:* Wie können Arbeitgeber und die Arbeitswelt die Situation pflegender Angehöriger besser unterstützen?
  - Aufgabe 6: Erforscht Möglichkeiten für Arbeitgeber und die Arbeitswelt, pflegende Angehörige durch flexible Arbeitszeitregelungen, Sonderurlaubsangebote oder andere unterstützende Maßnahmen zu entlasten. Entwickelt Ideen zur Sensibilisierung für die Bedürfnisse pflegender Angehöriger am Arbeitsplatz und zur Schaffung einer unterstützenden Arbeitsumgebung.

Figure 46: Task Description of Focus Group 5 - Workshop Phase I. (Page 2)

## **Backup-Fokusgruppe 5: Mentales Wohlbefinden**

### Workshop Phase 2:

- Um Sarah bestmöglich in ihrer burnoutnahen Situation zu unterstützen, erstellt eine umfassende Übersicht an Ressourcen und Möglichkeiten, die ihr bzw. anderen pflegenden Angehörigen helfen könnten, ihr mentales Wohlbefinden zu verbessern. Basierend auf den im Workshop Teil 1 ausgearbeiteten Fragen könnt ihr auch gerne die Erkenntnisse zusammenführen und eine Übersicht erstellen bzw. diese erweitern, sofern es weitere relevante Punkte gibt. Denkt dabei an eine Art "Mental Health Kit", das verschiedene Formen der mentalen Unterstützung umfasst.
  - Identifikation vorhandener Ressourcen und Unterstützungsangebote: Beginnt mit der Erfassung und Bewertung der bereits vorhandenen Unterstützungsangebote und Ressourcen für pflegende Angehörige. Untersucht die Verfügbarkeit von Beratungs- und Therapiediensten. Analysiert, welche davon am effektivsten sind und wo mögliche Lücken oder Defizite bestehen.
  - Entwicklung von "Selbstfürsorge-Ressourcen Kits": Erstellt Kits mit Ideen wie psychologische Beratung, Entspannungstechniken, Stressmanagement-Tipps oder Achtsamkeitsübungen, die pflegenden Angehörigen helfen könnten, ihre mentale Gesundheit zu pflegen und sich selbst zu unterstützen. Dabei soll der Fokus eher auf den Möglichkeiten und Angeboten liegen - anstatt sie konkret zu beschreiben - wie ein Katalog eines Shops.
  - Identifizierung von Gemeinschaften und Selbsthilfegruppen: Listet bestehende Netzwerke für pflegende Angehörige auf, die entweder online oder physisch eine Vernetzungsmöglichkeit bieten. Erstellt eine Übersicht, um Sarah und anderen Angehörigen die vorhandenen Möglichkeiten aufzuzeigen. Dies umfasst Plattformen, Foren, lokale Treffen und andere Formen der Interaktion, die pflegenden Angehörigen den Austausch von Erfahrungen und Unterstützung ermöglichen.
  - Identifizierung von Beratungs- und Therapieangeboten: Untersucht die Verfügbarkeit von Beratungs- und Therapiediensten für pflegende Angehörige und bewertet ihre Wirksamkeit. Schlagt gegebenenfalls Verbesserungen vor oder identifiziert Lücken, die geschlossen werden müssen.
  - Gedankenexperiment: Entwicklung einer Mentoring-Plattform: Denkt gemeinsam über die Machbarkeit einer Mentoring-Plattform nach, die sowohl professionelle psychologische Mentoren als auch Peer-Mentoren für pflegende Angehörige bereitstellt. Diskutiert, wie diese Plattform gestaltet werden könnte und welche Funktionen sie haben sollte, um den Bedürfnissen der Nutzer optimal zu entsprechen.

Figure 47: Task Description of Focus Group 5 - Workshop Phase II. (Page 3) 178