

University of Twente
Faculty of Behavioural, Management and Social Sciences
Psychology (MSc)
Health Psychology and Technology

Master Thesis

**Addressing the Needs and Challenges in Informal Dementia Care: A Qualitative
Exploration of e-Health in Cyprus**

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Acknowledgments

I would like to express my gratitude to the Ithaki Charity Organisation in Limassol, Cyprus, for their practical assistance in facilitating the interviews. I am sincerely honoured to have met all the informal caregivers who generously shared their time and insights for this study. I extend special thanks to my supervisors, Annemarie, for her continuous support in helping me realise my potential, and Stans, for her positive guidance throughout. And always, I am deeply thankful to my partner, mother, and father for being a constant source of strength throughout my academic, professional, and personal endeavours.

Abstract

Background: As the prevalence of dementia increases, so do the complexities associated with providing dementia care. In the midst of this, family members and friends have to shoulder the brunt of numerous caregiving responsibilities. This issue is particularly acute in Cyprus, where dementia care services are consistently found to be lacking, leaving informal caregivers to navigate daily challenges independently. Despite the promise of emerging technologies as a potential support system, their integration within this demographic remains largely unexplored.

Aim: This study aimed to explore the potential role of e-Health technologies in dementia care by uncovering the needs and difficulties faced by Greek-speaking informal caregivers of individuals with dementia living in Cyprus, as well as their expectations regarding different types of technological solutions.

Methodology: To achieve this objective, semi-structured interviews were conducted with 11 informal caregivers. Examples of contemporary technological interventions addressing safety and monitoring, communication, and care coordination in dementia care were presented. Thematic analysis was employed to examine the interview data, aiming to identify patterns within the quotes provided by the participants.

Results: In identifying the difficulties of informal caregivers, the important role of migrant care workers was highlighted. Caregivers with domestic assistance faced challenges with medication and behavioural issues, while those without this support struggled with daily activities and safety measures. To improve the provision of dementia care, the need for knowledge acquisition was primarily emphasised. Discussing the presented e-Health solutions, on the other hand, was dealt with concerns regarding their implementation. Once again, sociocultural aspects shaped their expectations, including living arrangements and employing care workers.

Conclusion: The findings underline the necessity for more in-depth investigation of personalised and targeted technological solutions for Greek-speaking caregivers of PwD in Cyprus, incorporating their experiences and perspectives to understand what contributes or hinders the adoption of e-Health in dementia care.

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Introduction

The global number of dementia diagnoses is projected to triple from 57.4 million in 2019 to 152.8 million in 2050 (Nichols et al., 2022). Furthermore, 75 to 90 percent of people with dementia (PwD) worldwide remain undiagnosed due to societal stigma and lack of awareness (Gauthier et al., 2021). Yet, regardless of whether they receive a formal diagnosis, PwD consistently endure a comparable burden. As highlighted by the Organisation for Economic Co-operation and Development (OECD, 2018, p.11), “even when they may be diagnosed, care systems are often fragmented, and the stigma surrounding dementia has led many people to believe that nothing can be done”. This issue is particularly pronounced in Cyprus, a country in South-Eastern Europe, where the national plan for dementia care has not been updated for over a decade, and the recording of dementia’s effects remains inconsistent. Hence, an urgent and critical imperative is to address the impact of dementia in Cyprus with new and innovative solutions, placing the affected population at the forefront of our efforts.

Living with Dementia

Dementia is a major neurocognitive disorder with a complex web of symptoms that can arise from a multitude of underlying diseases, such as Alzheimer’s, Parkinson’s, and small vessel disease (Gauthier et al., 2021). Preliminary indications of dementia may include memory impairment, spatial orientation and problem-solving difficulties, changes in mood and behaviour, social withdrawal, and reduced empathy towards others (World Health Organisation [WHO], 2023). The progression of dementia is influenced by a combination of individual characteristics and disease-related factors, which can vary both within and among patients (Melis et al., 2019). Nevertheless, advancing age remains the primary risk factor for developing this condition (OECD, 2021). Consequently, the increased ageing and population growth, as well as the absence of a cure for dementia, raise significant concerns for the future of those affected by the disorder (Lindeza et al., 2020; Nichols et al., 2022).

In Cyprus, the percentage of the Greek-speaking population living with dementia is anticipated to rise to 2.44% by 2050, a threefold increase from the 1.17% reported in 2018 (Alzheimer Europe, 2019). Prior to this decade, individuals seeking dementia care had to contend with a country that “was not in the position to offer comprehensive services for dementia” (Cyprus Ministry of Health, 2012, p. 46). As described in the latest national dementia plan published by the Cyprus Ministry of Health (2012), the primary healthcare of dementia

patients was mainly managed by the General Hospital or Mental Health Services of the Ministry of Health through various community centres in Cyprus. Day centres for cognitive enhancement were limited to the country's capital, Nicosia, while home care services in urban and rural areas were characterised as understaffed and in need of improvement. In some cases, these services were offered to PwD through volunteering, but did not meet the needs of care recipients or their carers (Cyprus Ministry of Health, 2012).

Inadequate care services may also extend to the migrant care workers or au pairs employed by family members to assist with dementia care. In particular, it is common practice in Cyprus to employ women from low-income Asian countries as domestic workers or au pairs who, in accordance with the legal requirements set out by the Civil Registry and Migration Department (n.d.), will often reside within the PwD's own residence. However, the nature of their services is still not formally documented and therefore cannot be assessed. Lastly, many other domains were identified to be lacking, such as specialised care facilities, legal frameworks, government funding for research, awareness campaigns, and expanded access to medication treatments (Cyprus Ministry of Health, 2012).

Caring for Dementia

As the condition of dementia advances, it brings forth physical, psychological, social, and economic challenges that extend beyond the patients themselves to their caregivers, families, and society at large (WHO, 2023). And as family members and friends are a crucial and often primary source of support in dementia care, they bear the heaviest burden across all these domains (OECD, 2018). According to Boyle (2023), the stages of dementia have varied implications for caregivers, from proactive decision-making in the early stage to increased involvement in managing neuropsychiatric symptoms in the middle stage, and escalating care demands and focus on palliative care in the late stage. This negative trajectory of the illness can erode the informal caregivers' self-perception of quality of life (QoL), and the presence of behavioural and psychological symptoms will further increase the distress of caregivers (Frias et al., 2020; Mukherjee et al., 2018).

Caregiver distress can, in turn, create a self-perpetuating cycle with detrimental consequences for both the caregivers themselves and the PwD under their care. For dementia patients, Stall and colleagues (2019) identified several potential outcomes resulting from caregiver distress, including their institutionalisation, exacerbation of behavioural and psychological symptoms, diminished QoL and functioning, challenges related to nutrition and feeding, instances of elder abuse, heightened healthcare utilisation, and increased costs. As for

the dementia caregivers, Wilson and colleagues (2019) observed that higher levels of distress were linked to more severe depressive symptoms among these individuals. Other researchers found that family caregivers would experience caregiver-related distress in their health, schedule, or finances, depending on their relationship with the PwD (Wawrziczny et al., 2020).

While there is relatively limited research on this topic in Cyprus, evidence suggests that the affected population of the island faces similar challenges. Earlier studies conducted within Greek-speaking Cypriot communities indicated that informal caregivers of PwD commonly experience feelings of burden, depression, moderate QoL, and low social capital (Papastavrou et al., 2014; Papastavrou et al., 2015; Papastavrou et al., 2012). Nearly a decade after, a study by Grigoriou and colleagues (2022) described similar findings, with informal caregivers reporting adverse effects to their physical well-being, daily activities, and overall health as a result of attending to a dementia patient's needs.

Moreover, the socioeconomical situation of Cyprus can exacerbate these challenges further. As identified in the latest national dementia plan, informal caregivers living in Cyprus often lack proper training and allowances to support their loved ones with dementia on a daily basis (Cyprus Ministry of Health, 2012). The issue of allowances, in particular, reflects a broader challenge inherent in the country's organisation of health. In brief, the Cypriot health system was historically divided between a publicly funded sector and an unregulated private sector, causing issues like resource imbalances, high out-of-pocket payments, unequal access, long waiting lists, and inefficiency. The introduction of the new General Healthcare System (GHS), *GeSY*, in June 2019 aimed to gradually bridge this division by expanding coverage, raising the quality of publicly provided care, and reducing service fragmentation (OECD/European Observatory on Health Systems and Policies, 2019). Nevertheless, since the inception of the national dementia plan and the implementation of the GHS, the Cyprus Ministry of Health has not provided an official update on the progress of addressing the abovementioned issues.

Using Technology in Dementia Care

Given the diversity of challenges experienced in dementia care, the overarching objective persists to prioritise solutions that effectively provide social and professional support to informal caregivers, thereby promoting the delivery of care and improving the QoL for caregivers and care recipients (Grigoriou et al., 2022; Frias et al., 2020). To this end, a growing range of technological approaches have emerged as viable means of supporting elderly care provision. State-of-the-art advancements such as tele-Health, robotic nursing, ambient assisted

living (AAL), and assistive robotics have the potential to provide physical and/or emotional assistance to older adults living in nursing homes or their own residences, while serving as valuable aids for formal and informal caregivers (Christoforou et al., 2020).

Specifically for dementia care, many electronic health (e-Health) solutions have been found to primarily target informal caregivers, as noted by Bastoni and colleagues (2021). Technologies designed to assist caregivers without requiring direct involvement from PwD often serve purposes such as (1) monitoring PwD's lifestyle, health, and safety using sensors, (2) providing online interventions for caregiver support, (3) using GPS for outdoor location tracking to enhance safety, and (4) offering online platforms for education and information sharing (Bastoni et al., 2021). These findings align with a literature review conducted by Pappadà and colleagues (2021), which also highlighted the positive impacts of implementing such technologies. The benefits encompassed improving the emotional well-being of caregivers by reducing symptoms of depression, anxiety, and stress; facilitating the development of decision-making skills, knowledge acquisition, and self-confidence; as well as fostering positive social interactions associated with caregiving, such as bonding with the care recipient (Pappadà et al., 2021).

In Cyprus, however, the integration of technology in dementia care is still in its nascent stages, focusing mainly on delivering online educational platforms and interventions for caregivers. An important contribution to this was made by Efthymiou and colleagues (2019), who translated and adapted the e-Health Literacy Scale (e-Heals) for Greek-speaking caregivers of PwD living in Greece and Cyprus, in an attempt to measure and enhance this population's e-Health literacy. This laid the foundation for Cyprus' involvement in European-funded projects, such as eLILY and eLILY2, which aimed to deliver a blended training program (combining face-to-face and eLearning courses) for informal caregivers of frail older people and PwD, as well as nursing students and nurses working with older adults (Efthymiou & Papastavrou, 2023). While these initiatives pave the way for improving the digital skills of caregivers in Cyprus, their practical implementation remains uncertain and other aspects of dementia care technologies remain insufficiently explored.

On one side, for the successful integration of technological solutions in healthcare, an important condition among others is to ascertain their acceptance among the intended users. Jaschinski and colleagues (2021) emphasised this point by introducing a conceptual model of AAL acceptance. Their study revealed that the inclination to utilise AAL technology, as well as e-Health technologies broadly, was determined by the user's attitude towards using the

technology, social and personal norms, and perceived behavioural control. Similarly, Bastoni and colleagues (2021) used the NASSS framework (see Greenhalgh et al., 2017) to identify factors influencing implementation related to dementia condition, technological features, user's expected/perceived value, and informal caregiver characteristics. However, such factors have not been explored for informal caregivers residing in Cyprus, despite their importance in the delivery of dementia care.

On another side, given the historical inadequacy of dementia care services in Cyprus and ongoing efforts to bridge socioeconomic disparities, exploring additional technological solutions in dementia care could help address these issues impartially. Vilans, the national centre of expertise for long-term care in the Netherlands, serves as a notable example of providing comprehensive information on the main contemporary healthcare technologies to the public, covering various aspects of dementia care such as safety and monitoring, communication, and care coordination. Through Vilans' (2024) Digital Care Knowledge Base, interested parties have access to independent insights on these technologies, their costs and benefits, as well as the contexts in which their application proves valuable. Having this knowledge-sharing resource promotes consistency in methodology, language, and research across organisations, thereby fostering the advancement of e-Health solutions. Consequently, this advancement has the potential to improve client well-being, support informal caregivers, and ease pressure on healthcare providers (Vilans, 2024).

Aim of the Study

Overall, while technology holds a plethora of potential advantages for dementia care, the current knowledge gaps regarding Greek-speaking Cypriot populations impede the thorough exploration of e-Health solutions yet. To start with, priority should be given to understanding the needs and challenges faced by informal caregivers as they navigate the various tasks encountered throughout the progression of the disease. By delving into their unique experiences and perspectives, the role of technological interventions in dementia care within this specific sociocultural context can be better assessed. Furthermore, following the example set by Vilans' Digital Care Knowledge Base, a range of these technologies should be introduced to gain insight into how expectations may differ based on the type of technology. Therefore, to achieve this dual objective, this study sought to answer the following research questions: (1) What difficulties do informal caregivers of PwD in Cyprus face in their daily care tasks? (2) What support do informal caregivers in Cyprus need for dementia care? (3) What

expectations do informal caregivers in Cyprus have regarding the utilisation of e-Health technology for safety and monitoring, communication, and care coordination in dementia care?

Methodology

Study Design

For the purposes of this study, a qualitative research design was utilised. The 11 informal caregivers of PwD involved in the research were questioned using a brief survey and a semi-structured interview scheme. Some elements of the interview scheme drew inspiration from the AAL Acceptance Survey developed by Jaschinski and colleagues (2021). These components focused on the interviewee's attitudes, social norm, and personal norm towards e-Health technological solutions. However, the overall structure of the interview was flexible, accommodating the varying levels of familiarity with technology among informal caregivers. This approach was chosen to allow caregivers to freely share their unique experiences, thoughts, and preferences, and therefore to enhance the depth and richness of the collected data.

Participants and Procedure

Participants were recruited in person, by telephone, and through leaflets over a three-week period from July to August. Inclusion criteria were that the participants spoke either Greek or English, were aged 18 years old and above, resided in Cyprus, and were or are informal caregivers for community-dwelling PwD. In cases where a person had ceased to provide informal care due to the passing of the individual with dementia, the time limit was set at five years from the individual's demise. Those who exceeded this threshold were excluded from the data collection process. The primary means of reaching out to potential respondents was facilitated through the Day Centre of the Ithaki Charity Organisation which is located in Limassol, Cyprus. The facility provides cognitive and neuropsychological assessments for the general public, conducts psychoeducational seminars for dementia caregivers, and offers both individualised and group support to PwD. In addition to this population, convenience sampling was employed to search for other potential participants who were residing in Limassol.

In total, 14 informal caregivers were invited to join the study. Among those who agreed to participate, a group of 11 individuals fulfilled the inclusion criteria. 10 were Greek-speaking Cypriots, while one spoke English. Once their participation was confirmed, an appointment for the interview was made. The entire interview procedure was estimated to take between 30 to

60 minutes. The interviews took place in a private room at the Day Centre, during the hours when informal caregivers were dropping off or picking up their loved ones with dementia. This scheduling was implemented to ensure minimal interference with their daily routines. It should be noted, however, that one interview was conducted at the participant's home. Prior to each appointment, participants were prompted to thoroughly review the information letter, with the option to do so again at the start of the meeting. After this, the informed consent form would be signed and participants were reminded that, as outlined in the information letter, interviews would be recorded in audio format and then transcribed and translated into text. The data collection process would then begin.

Materials

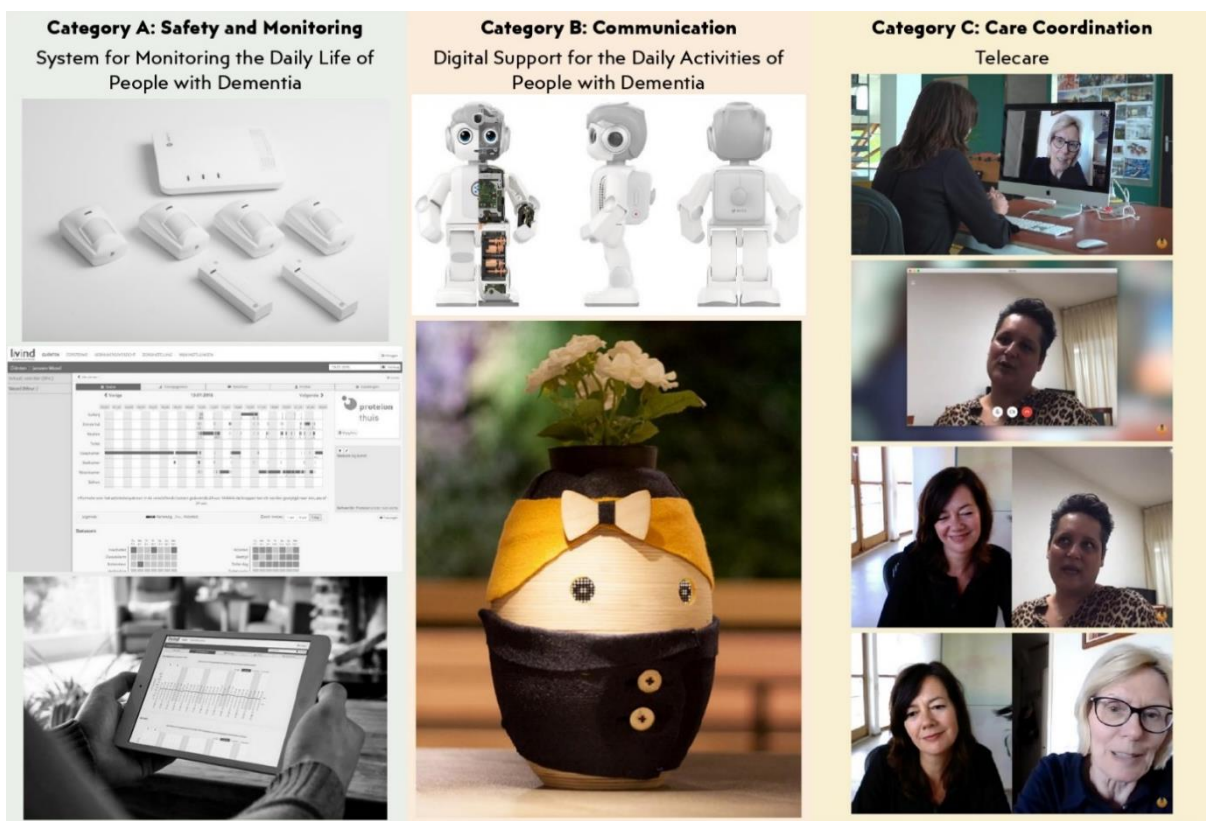
The data collection process commenced with the administration of a document comprising 16 closed-ended and short open-ended questions (see **Appendix A**). The main objective of this survey was to collect demographic information about the participant and the PwD to whom they provide or provided informal care, as well as to ascertain fundamental characteristics of this caregiving relationship. After completing the questions, the researcher proceeded with the interview. The interview scheme encompassed four distinct segments. For a detailed overview, refer to **Appendix B**.

Firstly, participants were asked to introduce themselves, delving into the details of their connection with the PwD to whom they currently or previously offered informal care. In addition, they were encouraged to elaborate on their experiences as an informal caregiver within the context of Cyprus. Secondly, participants were inquired about their familiarity with various e-Health technologies employed in dementia care. Following this, they were presented with a printed sheet featuring visual examples of interventions supporting safety and monitoring, communication, and care coordination in dementia care, which have been implemented in the Netherlands (**Figure 1**). The descriptions for each e-Health solution were extracted from the Vilans' (2024) Digital Care Knowledge Base, while the accompanying images were included solely to enhance comprehension and facilitate the upcoming discussion. The intent was to place greater emphasis on the technological specifications rather than the marketing aspects, hence detailed information about the products depicted in the images was intentionally omitted. It is important to note that all participants were given the same descriptions, although in some cases they requested more information.

Transitioning to the third segment of the interview, participants were invited to discuss the interventions that had been presented to them. The inquiries posed during this phase targeted

the respondent's attitude, social norm, and personal norm towards these e-Health technologies, with the ultimate goal of painting a more detailed and comprehensive picture of the expectations held by informal caregivers. In brief, these inquiries referred to the respondent's general feelings or opinions (e.g., overall impression, challenges of implementation), the response of their social environment and of the PwD, and their individual beliefs concerning the importance or not of such technologies. Finally, before concluding the interview, the researcher provided a summary of the discussion, offering participants one last opportunity to expand on any additional thoughts and ideas they wished to share.

Figure 1 Examples of e-Health Technologies to Support Safety and Monitoring, Communication, and Care Coordination in Dementia Care



Data Analysis

The process of data analysis in this study involved several steps, beginning with the transcription and translation of the interviews, which were initially stored in Microsoft Word. These transcripts were then transferred to ATLAS.ti 23, a software tool used for qualitative data analysis. Thematic analysis, a method that aims to distinguish and clarify underlying patterns or themes embedded in datasets, was used to analyse the data collected from the interviews (Braun & Clarke, 2006). Braun and Clarke (2006) further elaborate on this analytical process by outlining the six sequential steps of acquainting oneself with the dataset, formulating

preliminary codes, combining codes into themes, reviewing themes, defining themes, and producing the report.

For this study, data familiarisation involved multiple reading of the transcribed and translated interviews, with initial ideas regarding the codes noted down. Subsequently, interesting data features were systematically identified and highlighted across the dataset using ATLAS.ti 23. This process facilitated the generation of codes. Once the data was organized according to each code, the search for potential themes commenced. Reviewing and defining these themes was the most time-consuming phase, as it was an iterative process where constant adjustments were made and additional themes emerged. The goal was to clearly review, define, and refine each theme and the overarching narrative of the analysis. The result of this process is provided in **Table 1**. Finally, having concluded on specific main themes, subthemes, and codes, a report was produced which will be presented in the following section.

Table 1 Overview of the Main Themes and Subthemes

Research Question	Main Theme	Subthemes
What difficulties do informal caregivers of PwD in Cyprus face in their daily care tasks?	1. Difficulties in dementia care	1.1. Assistance with ADLs 1.2. Providing emotional support and companionship 1.3. Monitoring and managing behavioural symptoms 1.4. Supervising and ensuring safety 1.5. Medication management 1.6. Managing appointments and coordinating healthcare services 1.7. Managing finances and legal affairs
What support do informal caregivers in Cyprus need for dementia care?	2. Needs related to dementia care	2.1. Proactive safety measures 2.2. Knowledge acquisition 2.3. Supportive systems
What expectations do informal caregivers in Cyprus have regarding the utilisation of e-Health technology for safety and monitoring, communication, and care coordination in dementia care?	3. Expectations regarding e-Health technology in dementia care	3.1. Safety and monitoring 3.2. Communication 3.3. Care coordination 3.4. All e-Health technologies

Ethical Considerations

The Ethical Committee for Behavioural, Management and Social Sciences (BMS) at the University of Twente reviewed and granted approval for this research project under the reference number 230981. In handling the information provided by the respondents, the study adhered to the regulations of the General Data Protection Regulation (GDPR) as outlined by European Union Privacy Law. This encompassed the anonymisation of participants' demographic data, survey responses, and audio recordings and transcriptions from the interviews. Following the completion of the research, these records are to be promptly and

permanently destroyed. Additionally, in the interest of transparency, each participant received both oral and written explanations of how their data would be handled and was provided with the researcher's contact information for any inquiries or further clarification they may have desired.

Results

Description of the Study Group

A detailed description of the study group's demographics is provided in **Table 2**. Overall, all informal caregivers participating in this study were female, with ages ranging from 25 to 87 years. According to their survey responses, the majority of participants reported having attained tertiary education and were presently either full-time employed or retired. Notably, one participant, who is currently unemployed, was working full-time while caring for their loved one with dementia. This is the only participant who ceased to be an informal caregiver five years ago due to the passing of the PwD. Furthermore, most respondents indicated that they have been providing informal care for a period of two to five years, while weekly caregiving hours varied from less than 10 to over 40 hours. Of the 11 participants, six were the primary informal caregivers of the PwD, yet almost all acknowledged the involvement of additional informal caregivers, such as family members or the domestic assistant. Domestic assistants, in particular, were all women from low-income Asian countries, employed to support dementia care on specific days each week, with a minimum commitment of 10 weekly hours. In some instances, these individuals functioned as au pairs, offering 24-hour assistance to the PwD.

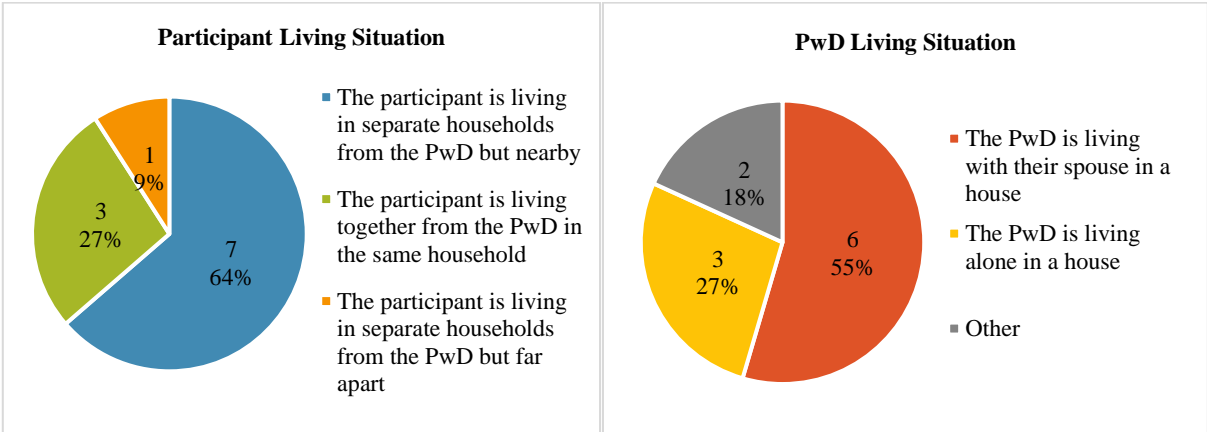
In terms of current living situations (see **Figure 2**), most informal carers lived in separate households from the PwD but within close proximity, such as on different floors of the same building. Conversely, only one respondent mentioned residing in a municipality which was geographically distant from the PwD's household. As for their care recipients' living situation, eight respondents indicated that the PwD shared their residence with a spouse and three reported that the PwD lived independently. It is also noteworthy that two participants had difficulties in determining the living situation of their care recipients. This issue was due to the aforementioned common practice in Cyprus, where migrant care workers serve as au pairs who often reside or are consistently present within the same household as the PwD.

Table 2 Demographic Information of the Participants and the Persons with Dementia

Participant ID	Age	Sex	Highest Educational Level	Current Job Status	Weekly Paid Hours	Relationship to PwD	Age of PwD	Gender of PwD	Primary Informal Caregiver	Other Informal Caregivers Involved:		Years as an Informal Caregiver	Weekly Hours of Informal Caregiving
										Family Members	Domestic Assistant		
A	45	Female	Tertiary education	Employed full-time	40	Child	77	Female	No	Yes	Yes	2–5	10–20
B	27	Female	Tertiary education	Employed full-time	40	Grandchild	80	Female	No	Yes	Yes	1–2	<10
C	81	Female	Tertiary education	Retired	Not applicable	Spouse	81	Male	Yes	Yes	No	2–5	>40
D	70	Female	Secondary education	Retired	Not applicable	Spouse	81	Male	Yes	No	No	1–2	>40
E	48	Female	Tertiary education	Employed full-time	38	Child	78	Male	Yes	Yes	Yes	2–5	<10
F	85	Female	Primary education	Retired	Not applicable	Spouse	83	Male	Yes	Yes	Yes	2–5	>40
G	25	Female	Tertiary education	Employed full-time	40	Grandchild	81	Female	No	Yes	Yes	2–5	<10
H	87	Female	Tertiary education	Retired	Not applicable	Sibling	85	Female	Yes	No	Yes	>5	>40
I	57	Female	Tertiary education	Unemployed (employed full-time while the PwD was alive)	Not applicable (40 while the PwD was alive)	Child	82 (age at the time of passing)	Female	Yes	Yes	Yes	>5	>40
J	51	Female	Tertiary education	Employed part-time	Unknown	Child	72	Female	No	Yes	Yes	2–5	<10
K	40	Female	Tertiary education	Employed full-time	40	Child	77	Male	No	Yes	No	0.5–1	30–40

Abbreviations: *PwD*, Person(s) with Dementia

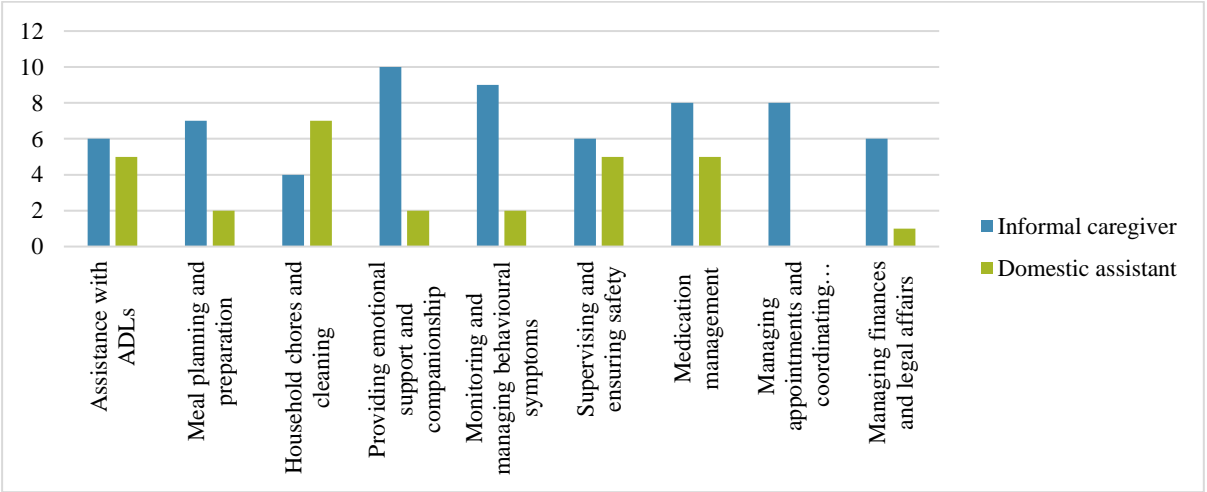
Figure 2 Current Living Arrangements of the Participants and the Persons with Dementia



Abbreviations: *PwD*, Person(s) with Dementia

Finally, when participants responded to the survey questions regarding their caregiving tasks, the vast majority highlighted providing emotional support and companionship as their main responsibility (see **Figure 3**). Subsequently, in a descending order, other caregiving tasks identified were monitoring and intervening in behavioural issues, managing medication, coordinating appointments and healthcare services, planning and preparing meals, assisting with activities of daily living (ADLs), ensuring safety, and overseeing financial and legal matters. The task least performed by informal caregivers was household chores and cleaning. More specifically, only four caregivers took on household responsibilities, with the prevailing sentiment being that such tasks were predominantly carried out by migrant care workers. As previously mentioned, these domestic assistants were recognised as key contributors to informal care, whether through regular visits or by residing the PwD, and therefore took on a significant number of the caregiving responsibilities.

Figure 3 Overview of the Tasks Performed by Informal Caregivers and Domestic Assistants



Abbreviations: *ADLs*, Activities of daily living

Theme 1: Difficulties of Informal Caregivers in Cyprus with Dementia Care Tasks

During the first part of the interview, participants were prompted to reflect thoroughly on the difficulties associated with caring for a PwD. This led to the identification of numerous codes representing limitations, adverse situations, and heightened challenges faced by the informal caregivers. All codes were then categorised into subthemes based on the specific caregiving tasks they addressed. For a summary of the subthemes and codes under this main theme, refer to **Table 3**.

Table 3 Summary of Informal Caregivers' Difficulties with Dementia Care Tasks

Subthemes and Codes	Definition of Code	Mentions ^a	Participants ^b
Assistance with ADLs^c			
Facing resistance	Difficulty for PwD to accept the help they receive.	2	2
Constant forgetfulness	Dealing with PwD's forgetfulness and the need for constant reminders.	2	1
Bearing sole responsibility of in-house matters	Feeling a sense of personal responsibility for taking care of the house alone.	1	1
Providing emotional support and companionship			
Loss of personal independency	PwD's dependency restricts personal space for informal caregivers.	2	2
Work-induced distance	Strained relationship due to a demanding work schedule.	2	1
Monitoring and managing behavioural symptoms			
Addressing incidents of violence	Dealing with the PwD's physical aggression or mistreatment towards the domestic assistant.	3	3
Supervising and ensuring safety			
Demanding nature of supervision	Constant and increasing need for supervision when caring for PwD.	2	2
Adhering to strict security measures	Routinely implementing strict measures to ensure the PwD's safety.	2	1
Physical limitations	Difficulty in ensuring safety due to the physical constrains of the informal caregiver.	1	1
Medication management			
Weighing the risks of medication side effects	Scepticism about the effectiveness and safety of medication for dementia.	4	3
Daily challenges in administering medication	Struggling to ensure consistent and effective medication management.	2	1
Concerns about relying on the domestic assistant	Raising questions about relying on the domestic assistant for medication administration.	1	1
Managing appointments and coordinating healthcare services			

Various coexisting health problems	Facing a life consumed by medical issues and healthcare services.	1	1
Lack of state support	Feelings of frustration about the state failing to provide essential dementia care support.	1	1
Lack of personalised care	Questioning the feasibility of tailoring care given the increasing number of dementia patients.	1	1
Managing finances and legal affairs			
Risk of financial exploitation	Difficulty for PwD to manage finances, leading to financial exploitation.	2	1

Abbreviations: *ADLs*, Activities of daily living; *GHS*, General healthcare system; *PwD*, Person(s) with dementia

^a The total number of times a code was mentioned in all interviews.

^b The number of different participants that mentioned a code.

^c Includes the tasks of bathing, feeding, and household cleaning.

Delving into the care task of **assistance with ADLs**, this subtheme revealed the difficulties in prompting PwD to carry out basic daily activities. In detail, Participant D highlighted the impact of the PwD's *constant forgetfulness* in dressing, an activity that consistently requires her reminders and assistance. Participant C expressed an overwhelming sense of *personal responsibility for managing household affairs*, despite suggestions of her daughters to hire help. Accepting help was also difficult for some of the care recipients, as other informal caregivers mentioned *facing resistance* in such matters. Participant E faced this resistance with her care recipient when she introduced a migrant care worker and the PwD reacted negatively, refusing to accept the worker's help in his home. For Participant J, on the other hand, resistance was experienced on a personal level. Specifically, the PwD was reluctant to accept the caregiver's assistance in selecting and organising her clothes. In the words of the respondent, this reflected a broader struggle of the care recipient in adapting to external help:

“Or changing her clothes- she took them off and then we realised that she was wearing the same ones again. She didn't understand that she had to change them... It wasn't easy for my mum to accept that we have to choose the clothes for her and put them there for her to wear. ‘Why? As if I don't know how (to do it)?’ she asked. ‘Why are you doing this?’ she said to my sister who was trying to line up the clothes in order to make it easier for her.”

Regarding the care task of **providing emotional support and companionship**, Participant E expressed the challenges of maintaining a close relationship due to her demanding work schedule, highlighting the limited time available to spend with the PwD. Her statements underscored the emotional toll of this *work-induced distance* and the worry that arises from

being away for extended periods. Another unpleasant side of this responsibility was the *loss of personal independency* within their relationships. In two cases, informal caregivers expressed how their loved ones with dementia have become overly dependent on them, restricting their ability to engage in basic personal activities without constant supervision or interruption. This situation is best captured in Participant C's quote:

“We were being very independent as a couple... And now he's totally dependent on me, he can't let me out of his sight. And we're together all the time. If I go to the toilet, if I push the door too - ((knocks on table)) 'You alright? You alright?'. Literally, that! I can't have a bath or a shower, just having a bath or a shower on my own, 'You alright?' and two minutes he is there to see- he needs someone.”

For the care task of **monitoring and managing behavioural symptoms**, only one code was identified which revolved around the difficulty of *addressing incidents of violence* caused by the PwD. Specifically, respondents recounted episodes of aggression towards the migrant care worker which, as illustrated in Participant B's statement below, involved locking, attacking, yelling, and throwing their belongings outside. Such situations necessitated the caregiver to either step in and address distress calls from the domestic assistant or navigate negative responses from the PwD, which could involve feelings of intrusion and dissatisfaction with the hired help.

“Well the thing is that lately she's been a little aggressive and I had to go there once or twice with my dad because the girl [Note: 'girl' as in domestic assistant] called us saying 'She's yelling at me', and she took her things and threw them outside. Uh, and we had to go along with it, in a way, because later she of course forgot. Five minutes after it was like this never happened. She didn't remember that she hit her and so we went along with it.”

As for difficulties that occurred when **supervising and ensuring safety**, participants highlighted the *demanding nature of supervising* a PwD, as it requires their constant presence and limits their ability to leave their care recipient unattended, even for short periods. Moreover, Participant C mentioned her inability to lift her care recipient who was frequently falling, indicating the impact of *physical limitations* on the PwD's independence and the caregiver's role. This participant also discussed the overwhelming necessity to *adhere to strict security measures* after the PwD had a concerning wandering incident. In order to carefully monitor and protect her care recipient from potential risks or incidents, Participant C maintained a vigilant

night routine where she locked the doors and hide the keys of the house. As she explained in the following quote:

“I have to remember every night to check around, make sure the doors are all locked, hide the keys and then I have to get up as soon as there’s light and put all the keys back so that he doesn’t realise he’s being locked in, because he’d get upset about that. It’s quite trying, it’s quite a work.”

In relation to **medication management**, three interviewees discussed the challenge of *weighting the risk of medication side effects*. Their quotes expressed scepticism about medication risks, either by linking the PwD’s cognitive decline to past surgeries or by questioning the effectiveness and safety of prescribed drugs. Overall, their perspective implied a cautious approach to medical recommendations. Additionally, Participant G raised her *concerns about relying on the domestic assistant* for medication administration, doubting the consistency and accuracy of the au pair’s ability to dispense pills daily and at the correct times. As for Participant I, her quotes depicted the *daily challenges in administering medication*, including the effort to obtain pills, monitoring intake, and dealing with the PwD discarding medication. As summarised in her following statement:

“And I gave (the medication) to her every day, every single day. She used to go to the hospital herself, drive and go get the pills. Well, then she couldn’t, so I had to go. But the process of finding the pills, taking them, checking how she would take them, it was very tiring.”

The care task of **managing appointments and coordinating healthcare services** was also met with some difficulties. As described by Participant C, her life with the PwD was consumed by *various coexisting health problems*. In her quotes, there was a feeling that their existence revolved solely around healthcare services, with frequent visits to the hospital and many medical appointments. Participant E focused on the *lack of state support*. This informal caregiver expressed great disappointment that a state, which she felt was benefiting from years of citizen contributions, failed to provide essential support. As such, she questioned the fate of the PwD when family support is lacking. In addition, Participant G reflected on the *lack of personalised support* that came with the recently updated GHS, questioning the feasibility of tailoring care to the specific needs of PwD given the increased number of patients doctors encounter. In the following quote, the respondent explained:

“I don’t know how personalised dementia care can be because a doctor, okay, how many people do they see every day, especially now with the GHS, it’s a little bit more difficult, they see a lot more people, so yeah.”

The last subtheme and responsibility of informal caregivers, **managing finances and legal affairs**, was discussed exclusively by Participant E. The interviewee referred to two incidents where the PwD’s inability to manage his own finances made him susceptible to manipulation and deception by others. As summarised in her statement below, the *risk of exploitation* posed an ongoing difficulty, which forced the informal caregiver to assume control over her care recipient’s finances.

“Because the truth is that some people fooled him... And then we realised that he couldn’t manage his finances and now it’s been about a year since I took over and I have his money and I’m writing it down, so that we know what’s going on and so he doesn’t fall victim again.”

Theme 2: Needs of Informal Caregivers in Cyprus Regarding Dementia Care

Following descriptions of the difficulties experienced with dementia care tasks, participants were asked to discuss their needs as an informal caregiver in relation to these responsibilities. Consequently, some participants listed a number of needs, the subthemes and codes of which are summarised in **Table 4**.

Table 4 Summary of Informal Caregivers’ Needs Regarding Dementia Care

Subthemes and Codes	Definition of Code	Mentions^a	Participants^b
Proactive safety measures			
Emergency communication device	Having the PwD carry a basic mobile phone as an emergency communication device.	1	1
Employing a domestic assistant	Safety-related need for a live-in domestic assistant.	1	1
Secure living environment	Prioritising a secure living environment for the PwD.	1	1
Knowledge acquisition			
In-depth understanding of disease progression	Desire for a clear understanding of the progressive nature of dementia.	2	2
Communication-related advice	Advice on how to better interact with the PwD.	2	2
Better informed administration of medication	Hopes to have avoided difficulties in the informal caregiver’s medication management.	1	1
Supportive systems			
Increase of dementia-related facilities	Need to address current lack of dementia-related facilities.	1	1

Sharing care tasks with family	Helpfulness of having another informal caregiver involved in dementia care.	1	1
Mobility assistance	Having a service to transport PwD when needed.	1	1

Abbreviations: *GHS*, General healthcare system; *PwD*, Person(s) with dementia

^a The total number of times a code was mentioned in all interviews.

^b The number of different participants that mentioned a code.

Starting with **proactive safety measures**, this subtheme captures the efforts of informal caregivers to timely and effectively protect their loved ones with dementia. While one interviewee focused on the need for a PwD to have an *emergency communication device* in case of an accident, another prioritised the need for having a *secure living environment* to avoid potential hazards at home for their care recipient. In addition, Participant G expressed the necessity of having someone live with the PwD, particularly *employing a domestic assistant*. As she explained in the following statement, the decision was motivated by concerns about the PwD’s safety, citing instances of potential dangers such as leaving the gas on and the risk of falling without immediate assistance:

“Well I told them that this is no longer possible, someone has to come live with her. She started to get a little dangerous in that she could cook and let off the gas, so to speak, we had that happen to us. Or she could fall down and not have someone there, and she could get hurt worse. Or she might want to contact us and not remember our phone numbers, even if they’re written on a piece of house paper. So yeah, definitely having a domestic helper was something that needed to be done.”

Secondly, the subtheme of **knowledge acquisition** refers to the basic yet important need of understanding how to address dementia-related issues. Participant A described a situation where her father, the primary informal caregiver of the PwD, faced difficulties in managing the medication. Specifically, her father was influenced by stress, the desire to be on top of everything, and potential mistakes due to age and unawareness. As such, the interviewee implied a need for *better informed administration of medication* in these situations, to properly guide both informal caregiver and care recipient. Another request was for *communication-related advice*, as interviewees reported feeling uncertain on how to navigate a situation in which the PwD may communicate statements that are not grounded in reality or are out of touch with current context. Moreover, participants expressed a desire for *in-depth understanding of the disease’s progression*, with Participant C emphasising the importance of knowing the stage

of dementia to determine the effectiveness of drugs and to better comprehend the challenges involved in caregiving:

“That’s something I’d like, to know what stage he’s at, because they say- have you heard about the drugs and that they’re testing for Alzheimer’s? They’ve found stuff- but it says every time ‘Only at the very onset of the disease’, so if you’ve been diagnosed when you’re 50 and start taking the drugs by the time you’re 80, you know, you’re not as far deteriorated as he is. So I just think I’d like somebody to tell me what stage is he at.”

Lastly, the subtheme of **supportive systems** is characterised by the participants’ need for daily assistance. One statement suggested that there is a growing need for *more dementia-related facilities*, like a gated village for older individuals. This informal caregiver described the lack of such facilities in Cyprus and underscored the necessity to have a safe environment where PwD can live independently yet have easy access to medical services and support. Another informal caregiver mentioned her desire to *share care tasks with family members*, who are available and willing to assist the PwD in situations when she is unable to. The third statement, as requested by Participant F, was for a form of *mobility assistance* within the context of the Day Centre. As stated in the following quote, the respondent proposed a service where PwD are picked up from their homes and transported to the centre, with the aim of easing the burden on caregivers:

“Yeah, to bring them in themselves, have the Day Centre pick them up from their home and bring them here. It would help the caregivers more.”

Theme 3: Expectations of Informal Caregivers in Cyprus Regarding e-Health Technology in Dementia Care

During the last part of the interview, when discussing e-Health technology for safety and monitoring, communication, and care coordination in dementia care, respondents shared a variety of positive and negative expectations. Many also ranked the options presented to them, arranging them in order from most to least likeable. While having more optimistic or pessimistic expectations did not correlate with the probability of adoption, it provided a better understanding of informal caregivers’ views. Additionally, it is notable that when expressing their negative expectations, many interviewees generalised their concerns to include all categories of e-Health technologies rather than focusing on a particular one. For a summary of the identified subthemes and codes, as well as their accompanying definitions, refer to **Table 5**.

Table 5 Summary of Informal Caregivers’ Negative and Positive Expectations Regarding e-Health Technology

Subthemes	Negative Expectations				Positive Expectations			
	Codes	Definition of Code	Mentions ^a	Participants ^b	Codes	Definition of Code	Mentions ^a	Participants ^b
Safety and monitoring	Presence of third parties	Inability to implement e-Health technology due to others visiting or living with the PwD.	1	1	Peace of mind	Seeking peace of mind when away or PwD is at risk.	4	3
					Increase of personal time	Allowing more personal moments as an informal caregiver.	1	1
Communication	Requires third-person assistance	Need for constant explanation on how to use e-Health technology.	2	2	Ensure timely medication administration	Address potential barriers with administering medication to the PwD.	1	1
	Dismissing commands	PwD’s forgetfulness limits the ability to perform commands by the e-Health technology.	1	1				
	Causing nervousness	Fear that the e-Health technology will frustrate the PwD.	1	1				
	Limits human interaction	Reducing opportunities for in-person connection.	1	1				
Care coordination	PwD’s inability to actively participate	PwD’s understanding of technology limits active use e-Health technology.	1	1	Easily applicable with younger generations	Ability of younger doctors, more familiar with technology, to address healthcare concerns using technology.	2	2
	Replaceable with existing technologies	e-Health technology has no added value to existing technological devices.	1	1	Address mobility issues	Practical solution for PwD with mobility issues.	1	1
					Visual connection	Allowing involved parties to visually connect with others.	1	1
All e-Health technologies	Preference of in-person support	Prioritising human-to-human interactions over e-Health technologies.	2	2	-	-	-	-
	Requires familiarity with technology	Requirement that both PwD and informal caregiver understand how to use the technology.	1	1				

Rejection by important others	Social circle disapproves the implementation of e-Health technologies.	1	1
Lack of internet connection	Implementation not feasibility due to lack of internet connection.	1	1

Abbreviations: *GHS*, General healthcare system; *PwD*, Person(s) with dementia

^a The total number of times a code was mentioned in all interviews.

^b The number of different participants that mentioned a code.

The feedback on **safety and monitoring technology** was predominantly positive, with the majority of informal caregivers ranking it as the most likeable. At the same time, however, this subtheme had the fewest codes, as respondents provided limited insights into their expectations. Starting with the negative expectations, this e-Health technology for dementia care was associated with implementation issues. Participant K, in particular, acknowledged that the PwD is rarely alone in his home. More commonly, there are several individuals in his household, including his grandchildren. This factor raised doubts about the applicability of such devices in the PwD's house, as explained in her following quote:

“It’s not just my dad in the house, I mean now. There are many others, also the grandchildren and so on, so I don’t know whether it would be suitable for his case [Note: Refers to safety and monitoring technology]. He is not completely alone.”

In terms of positive expectations, safety and monitoring technology was anticipated to deliver two benefits. First, Participant C highlighted that it could *increase personal time*, enabling the informal caregivers to step away from the PwD. Consequently, this could become a valuable personal time that does not compromise the essential caregiving responsibilities. Second, respondents expressed a desire to use this technology for *peace of mind*. In their statements it was implied that having the ability to track and monitor the activities of the PwD, especially those who may wander or be vulnerable, would bring a sense of security. The following statement by Participant A summarised this expectation:

“I’m telling you, it would be good for a brief period of time [Note: Refers to safety and monitoring technology], that is, when my dad is away from 5 to 7 and it has already recorded his behaviours and so on... This would be good, and to immediately receive a notification... So this thing would be good if they have someone nearby who can run in case of danger.”

Communication technology was chosen as the second most likeable e-Health solution for dementia care by half of the respondents. Participant K discussed in more detail that incorporating such devices will be important to *ensure timely medication administration*. The informal caregiver spoke of her desire to have a technology serve as a reminder for medication, addressing issues of potential forgetfulness. Therefore, as it was implied in her statement, this would assist both informal caregivers and care recipients:

“I’d like the communication (technology) because uh, that would help my mum or the person who’s taking care of him- because my mum sometimes forgets to give him his medication too, so that would be... A reminder. For his medication.”

Regardless of being the second most likeable e-Health technology, most codes identified were related to negative expectations. One quote reflected scepticism about the effectiveness of giving commands through such devices, suggesting that PwD may forget or lack the capability to follow through unless explicitly reminded to do so. As such, there is the risk of the PwD *dismissing the commands*. Another quote focused on the risk of the technology *causing nervousness* to the care recipient, as they might struggle to use or handle it. The informal caregiver implied that this could potentially lead them to break the device apart. Two other quotes illustrated the difficulty to explain and operate the technology as an individual with dementia. Participants emphasised that such cases would *require constant third-person assistance*. Moreover, Participant G’s quote implied a risk of communication technology *limiting human interaction*. This respondent expressed the view that while technology, such as communication devices, may offer convenience, it diminishes the personal and human element. With this perspective, and as summarised in her quote, in-person interactions where care recipient and informal caregiver meet physically and share experiences could contribute to a much richer and meaningful relationship:

“Look, certainly anything to do with technology takes away a little bit of the human element, unfortunately. Uhm, I mean okay it would be nicer if it was me there saying to my grandmother ‘Grandma come get your pills’ and it wasn’t the robot saying it ((laughter)) [Note: Refers to communication technology]. But the fact is, going to the doctor and having her see you in person and talk to you, I guess there are some benefits to it, uh... I mean even the process, getting her in the car, getting her in the car, going for our ride and going to the doctor, walking, moving, uh it’s different, it’s a different experience than taking my cell phone from her and talking to the doctor, for example.”

Care coordination technology, on the other hand, was ranked as less likeable but only two codes related to negative expectations were identified. Participant C, for example, was concerned about the *PwD’s inability to actively participate* in the use of this technology due to his hearing problems and challenges in understanding conversational cues in online meetings. For Participant D, on the other hand, this e-Health solution was considered *replaceable with existing technologies* and therefore found no use for it. In the words of this respondent, the

functionality of seeing and talking to someone online can be adequately replaced by using a phone:

“What’s the use of this for me, for example [Note: Refers to care coordination technology]? Since I can use the phone to call, why would you need to see the other person to talk to them?”

Positive expectations regarding the use of care coordination technology were related with benefits such as being able to *address mobility issues* that a PwD might have. More specifically, Participant C understood that this technology could alleviate the challenge of dealing with a PwD who is bedridden or has difficulty getting into a car. Participants A and B were more positive about the technology being *easily applicable by younger generations of healthcare providers*. From their perspective, younger and more technologically adept doctors can make it easier for current and future dementia patients and caregivers to resolve healthcare-related issues using this tool. Furthermore, Participant I suggested that care coordination technology can elicit positive emotions by allowing participants to *visually connect* with others. In her following quote, she referenced the picture provided in **Figure 1** and highlighted that such connection can provide reassurance and a sense of well-being:

“The last one [Note: Refers to care coordination technology] brings me only positive feelings. They will see others like she does in the picture, do you see her? She sees her mom and is reassured. You’re reassured when you see her that you talked to her and she feels better.”

Ultimately, the additional subtheme referring to **all e-Health technologies** included a range of codes exclusively related to expressed negative expectations. Firstly, Participant B’s quote suggests that successful implementation of certain technologies in caregiving relies on the caregiver’s *familiarity with technology*. Therefore, this raises the concern of how older individuals without the assistance of technologically adept closed ones can embrace and use any of the aforementioned e-Health technologies. Participants F and K’s quotes reflect a strong inclination towards physical presence and traditional support systems. In one case, Participant F emphasised the comfort and satisfaction derived from the close proximity of their daughter to support with dementia care; in the other, Participant K advocated for the expansion of support centres, like the one by the Ithaki Charity Organisation, rather than relying on various technologies. In addition, Participant G’s quote underscored that many older individuals in Cyprus live in houses without internet access, hindering the use of technology dependent on online connectivity. And on a final note, Participant K’s quote expressed a general rejection of

all technologies by her family members, a disapproval which may be rooted in lack of belief in the diagnosis:

“My mum wouldn’t approve of it at all [Note: Refers to all technologies]. Because I’m telling you she still doesn’t believe it [Note: Refers to the diagnosis], she’s a little sceptical on this matter. Well, my brothers, I don’t think so either. Because- I don’t think so.”

Discussion

This study sought to unveil the difficulties and needs encountered by Greek-speaking informal caregivers of PwD in Cyprus, with the aim of exploring the potential role of e-Health technologies. The findings highlighted the significant impact of migrant care workers in the provision of care. Caregivers supported by a domestic assistant faced issues mainly associated with administering medications and monitoring and addressing behavioural symptoms. In contrast, caregivers lacking support from a domestic assistant experienced challenges primarily related to assisting with ADLs and ensuring the safety of the PwD. Highlighted in the results was also the imperative for caregivers to acquire more knowledge and skills to address dementia-related issues. When presented with examples of technological interventions for safety and monitoring, communication, and care coordination, all respondents voiced concerns about their practical implementation. Once again, sociocultural aspects such as living arrangements and the employment of domestic assistants shaped their expectations.

Research Question 1: What difficulties do informal caregivers of PwD in Cyprus face in their daily care tasks?

Eight out of the 11 participants received additional help from female migrant domestic assistants or au pairs in handling nearly all caregiving responsibilities. In essence, informal caregivers continued to be responsible for daily care activities, but the division of labour shifted: they primarily offered organisational and emotional support, while the care workers predominantly undertook physical tasks. This aligns with findings from research conducted in Taiwanese households, which identified a hierarchical care division between ‘mind work’ and ‘body work’ (Liang, 2018). However, as suggested in subsequent research, this does not imply a transition from being care providers to becoming solely care managers: family members, particularly women, continue to aid migrant care workers as needed, blurring the lines between

emotional and physical care tasks (Liang, 2021). Moreover, Yuan and colleagues (2022) noted that caregivers of PwD can find themselves increasingly involved in supporting domestic assistants as the disorder advances and more complex situations emerge. The present study further substantiates this statement by revealing that, while not having a domestic worker can increase difficulties in managing practical issues such as ADLs and safety, households with a domestic worker still face great challenges.

Most difficulties were attributed to the care task of medication management. Consistent with previous literature (Gench et al., 2021; Lee et al., 2019; Look & Stone, 2019), informal caregivers commonly took on the responsibility of managing a complex medication regimen while aiming to prevent errors that could endanger the well-being of PwD. Yet, participants struggled with determining whom to rely on to ensure the effectiveness and correct administration of medication. Similar concerns were identified in the research conducted by El-Saifi and colleagues (2019), wherein caregivers expressed feelings of inadequacy in administering medication to their care recipients due to the influx of varied, inconsistent, and contradictory information from different healthcare providers. In the current study, however, a distinct concern was also voiced about relying on the migrant care worker to adhere to this regimen. Other studies have associated this issue with language deficiencies and miscommunication (Heng et al., 2018); insufficient training or experience in relevant work (Liang, 2021); and differing cultural approaches to (dementia) care (Brooke et al., 2017). Nevertheless, the interplay of these factors within the demographic of this study remains unclear, underscoring the need for future research to delve into the intricate dynamics of medication management among dementia caregivers in Cyprus.

Furthermore, this study highlighted the important difficulties related to the care task of monitoring and addressing behavioural symptoms of PwD. Informal caregivers had to deal with incidents of violence and particularly acts of aggression or mistreatment towards the domestic assistant. A scoping review examining this issue among professional caregivers in home care settings revealed the factors that trigger these behaviours, including unmet needs of PwD, insufficient communication skills among professional caregivers, and the nature of the caregiving activities (Schnelli et al., 2023). By extension, these situations might increase caregiver burden as the primary caregiver has to support both the PwD and the affected domestic assistant (Yuan et al., 2022). Indeed, participants in this study were also tasked with the duty of attending to distress calls from the domestic assistant, as well as managing the feelings of intrusion or dissatisfaction experienced by the PwD. However, whether or not these

issues could be effectively resolved remains unknown. Hence, future interventions aimed at this demographic should once more acknowledge both the crucial contribution of domestic assistants and the possible challenges arising from their migrant background (e.g. language barriers, unregulated training processes).

Research Question 2: What support do informal caregivers in Cyprus need for dementia care?

In discussing possible means of supporting dementia care, participants highlighted some of their key needs. Central among these was the necessity for knowledge acquisition: the desire to improve their understanding regarding the disorder and to identify optimal strategies for addressing any arising issues. This was mostly related to the aforementioned difficulties in medication management, which informal caregivers hoped to have prevented from the onset of dementia. In line with this finding, El-Saifi and colleagues (2019) observed that early access to accurate information about dementia and its escalating consequences could empower caregivers to make well-informed decisions and advocate for their care recipients, ensuring they receive appropriate care. However, it is important to also take into consideration the potential barriers to obtaining this information. Prior research has highlighted that, although healthcare professionals have a potentially mediating role in reducing caregivers' concerns, there may be cases that lack adequate training or education on how to assist caregivers (Laparidou et al., 2019). Given the poor state of dementia care services in Cyprus (Cyprus Ministry of Health, 2012), similar challenges are likely to confront affected individuals in this country.

The need for dementia-related knowledge and skills to improve communication with the PwD was also emphasised. This, however, was mainly linked to the previously mentioned difficulties in monitoring and managing behavioural symptoms. Informal caregivers frequently experienced uncertainty in responding to statements from their care recipient that lacked grounding in reality or were disconnected from the current context. From the care recipient's perspective, Alsawy and colleagues (2019) discovered that PwD are aware of their interpersonal interactions and value others' emotional and physical presence in communication. To this end, the researchers suggested that caregivers should embrace person-centred approaches, including active listening, empathetic understanding, and recognition of the emotions and experiences of PwD, to foster meaningful interactions and enhance communication with them (Alsawy et al., 2019). Expanding upon this finding in future research within this Cypriot context may be crucial for addressing potential communication challenges arising from the unexpressed (and thus unmet) needs of PwD.

Research Question 3: What expectations do informal caregivers in Cyprus have regarding the utilisation of e-Health technology for safety and monitoring, communication, and care coordination in dementia care?

Introducing participants to the e-Health technology for safety and monitoring, communication, and care coordination in dementia care was accompanied by both positive and negative expectations. To this end, an essential next research step regarding this population involves incorporating these expectations to develop targeted technological solutions that meet the needs of caregivers more effectively. Therefore, emphasis should be placed on what shaped their expectations in the first place. Starting with surveillance technology, this was thought to be a useful proactive safety measure. Consistent with other studies (Vermeer et al., 2019; Sriram et al., 2019), this technological solution was anticipated to increase the independency and bring peace of mind to both caregiver and care recipient. However, for the households with a domestic assistant or au pair, its implementation was deemed impossible: the PwD was rarely alone and therefore recording and monitoring their behavioural patterns to alert the caregiver in cases of danger could be inaccurate. Perhaps, as proposed by Holthe and colleagues (2020), integrating this technology could become feasible through cooperative efforts between family members and care workers, who would implement it not as a standalone solution but as a component of a broader safety system for PwD.

Similarly, for the informal caregivers who resided in close proximity or within the same premises as the PwD, the use of telecare was considered irrelevant as it could be replaced by traditional solutions (e.g. calling the personal doctor via telephone). Conversely, it was anticipated to be helpful if one struggles with mobility or distance problems, ensuring continued access to care services for PwD. Nevertheless, the rise of telecare calls for a need to prepare PwD and their caregivers to better adapt to it. Hence, as suggested in literature, successful delivery of this technology should take into consideration the potential cognitive, visual, or hearing impairments of PwD, as well as the specialised training of their caregivers (Yi et al., 2021). As for the interventions focusing on communication-related aspects of dementia care, their unobtrusive and familiar design was favoured yet various concerns were voiced. In line with the findings of Bastoni and colleagues (2021), this included the seriousness of the PwD's condition, their own and the PwD's unfamiliarity with technology and reliance on others for help, problems with infrastructure, and their personal preference for in-person assistance over tech-based solutions. To overcome this obstacle and effectively develop and implement such technologies, using the NASSS framework has been recommended (Bastoni et al., 2021).

Strengths and Limitations

This study is not without limitations, particularly in terms of the depth and saturation of the data collected. On one hand, while the interview scheme was flexibly designed to accommodate the open sharing of experiences and the diverse levels of technology familiarity among participants, it often diverted attention away from the main topics of discussion. Therefore, certain research gaps emerged during the data analysis process that might have been prevented by piloting the interview questions or adhering to a more structured interview approach. On the other hand, in discussing their expectations about the presented examples of e-Health technologies, the majority prioritised agreeableness and refrained from details insights into their underlying thoughts. This could be related to a second limitation, namely the inclusion of a biased study group. The Ithaki Charity Organisation was the primary means of recruitment and it is plausible that the accommodating attitude of participants was shaped through their affiliation with it. Exploring the perspectives of informal caregivers from different backgrounds (e.g. other geographical settings) is an area for future research. Lastly, a limitation arises from the potential impact of the researcher's pre-existing interpretations of implicit language nuances, which could only be translated and transcribed with a certain degree of accuracy. Future studies involving Greek-speaking Cypriot populations should incorporate multiple authors in the data analysis to mitigate research bias and uncover underlying meanings within their expressions.

Importantly, despite the aforementioned limitations, this study is still unique in its attempt to understand the needs and challenges faced by Greek-speaking Cypriot informal caregivers of PwD and examine the potential role of e-Health technology in addressing these issues. Due to their limited exposure or familiarity with it within the context of Cyprus, this was also a novel topic to explore for most participants. Moreover, while recruitment was mainly facilitated through the Ithaki Charity Organisation, an overall heterogeneous sample was maintained by including various family members (e.g. spouses, siblings, grandchildren) providing care to individuals with different levels of dementia. As such, experiences from a broader spectrum of the disorder were uncovered. Additionally, the interview scheme remains a strong point of the research, as it was based on certain elements of the conceptual model of AAL acceptance by Jaschinski and colleagues (2021). More specifically, this proved useful in providing a theoretical foundation for understanding how this population perceives e-Health interventions, regardless of their familiarity levels with technology.

Conclusion

By placing emphasis on investigating the needs and difficulties of Greek-speaking informal caregivers who provide care for PwD in Cyprus, this study has revealed significant sociocultural characteristics that may influence the effectiveness and applicability of certain e-Health technologies. Presently, offering a comprehensive overview of these technologies marks an essential initial step toward identifying both the anticipated facilitators (e.g. the desire for peace of mind) and obstacles (e.g. the persistent presence of third parties in the home environment) in their implementation. Looking ahead, further exploration of the personal, societal, and cultural dimensions inherent in dementia caregiving within this context could prove pivotal in refining and tailoring technological interventions. Therefore, it is strongly recommended that the theoretical insights gathered herein be translated into practical solutions, by developing future e-Health technologies that will serve all informal caregivers in their daily caregiving endeavours.

Abbreviations

AAL: Ambient assisted living

ADL: Activities of daily living

BMS: Behavioural, Management and Social Sciences

e-Health: Electronic health

GHS: General Healthcare System

OECD: Organisation of Economic Co-operation and Development

PwD: Person(s) or people with dementia

QoL: Quality of life

VR: Virtual reality

WHO: World Health Organisation

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Appendix A: Participant Demographic Survey

Section A: Demographic Information

In Section A, we kindly request you to provide basic details regarding your background. These details include your birthplace, gender, level of education, employment status, and age.

- 1 What is your gender? Male
 Female
 Non-binary
 Prefer not to say
-
- 2 What is your highest level of education? Primary education
 Secondary education
 Tertiary education (e.g., college, university)
 Other: _____
-
- 3 What is your current job status? Employed full-time
 Employed part-time
 Self-employed
 Unemployed
 Student
 Retired
 Other: _____
-
- 4 If applicable, what is the number of weekly hours you engage in paid work?
-
- 5 What is your age?
-

Section B: Informal Caregiving to People with Dementia

In Section B, we kindly request you to share information about your relationship to the person with dementia and the level of care you provide. Generally, an informal caregiver is a family member, friend, or neighbour, who may lack professional healthcare training and expertise. These caregivers offer support, assistance, and companionship to individuals in need, helping them navigate daily activities and maintain a good quality of life.

- 1 What is your relationship to the person with dementia? Spouse / Partner
 Child
 Sibling
 Friend
 Neighbour
 Other: _____
-
- 2 What is the age of the person with dementia?
-

3 What is the gender of the person with dementia? Male
 Female
 Non-binary
 Prefer not to say

4 Are you the primary (main) informal caregiver of the person with dementia? Yes
 No

5 Are there any other informal caregivers involved in the care of the person with dementia? If yes, please write their relationship to the person with dementia in the answer. Yes, _____

 No

6 How long have you been providing informal care for the person with dementia? Less than 6 months
 6 months to 1 year
 1 to 2 years
 2 to 5 years
 More than 5 years

7 On average, how many hours per week do you dedicate to caregiving for the person with dementia? Less than 10 hours per week
 10 to 20 hours per week
 20 to 30 hours per week
 30 to 40 hours per week
 More than 40 hours per week

8 What is your current living arrangement with the person with dementia? Please select all that apply. Living together in the same household
 Living in separate households but nearby (e.g., same building)
 Living in separate households far apart (e.g., different city or village)
 The person with dementia is living in a nursing home or assisted living facility
 The person with dementia is living alone in a house
 The person with dementia is living with their spouse in a house
 Other: _____

9 Does the person with dementia receive support from a domestic assistant as part of their current living arrangement? Yes
 No

10 What tasks do you typically perform to support the person Assistance with activities of daily living (e.g., bathing, dressing, feeding)

with dementia? Please select all that apply.

- Medication management (e.g., administering medication, organising prescriptions)
- Monitoring and managing behavioural symptoms (e.g., agitation, aggression)
- Providing emotional support and companionship
- Supervising and ensuring safety
- Managing appointments and coordinating healthcare services
- Meal planning and preparation
- Household chores and cleaning
- Managing finances and legal affairs
- Other: _____

11 If applicable, what tasks does the domestic assistant typically perform to support the person with dementia? Please select all that apply. (If not applicable, please leave this question blank.)

- Assistance with activities of daily living (e.g., bathing, dressing, feeding)
 - Medication management (e.g., administering medication, organising prescriptions)
 - Monitoring and managing behavioural symptoms (e.g., agitation, aggression)
 - Providing emotional support and companionship
 - Supervising and ensuring safety
 - Managing appointments and coordinating healthcare services
 - Meal planning and preparation
 - Household chores and cleaning
 - Managing finances and legal affairs
 - Other: _____
-

Appendix B: Interview Scheme

1 Introduction – Needs and Difficulties in Dementia Care

1.1 Relationship with the person with dementia:

- “Would you like to tell me a few words about yourself and your relationship with [the person with dementia]? (e.g., “How many years have you been his/her informal carer?”)
- “What part of your life has changed the most since you learned about the person’s condition and took on the role of informal carer?” (e.g., living conditions, daily activities and responsibilities, relationship between you)

1.2 Experience as an informal carer of a person with dementia in Cyprus:

- “Could you describe your journey in the health care system in Cyprus, starting from before the diagnosis of dementia to the current stage?”
- “What are the current challenges you face when caring for your loved one with dementia? What problems do you face (e.g., infrastructure problems, social or interpersonal problems)?”
- “How have you tried/are you trying to resolve these challenges? What resources or strategies have you found/do you find helpful in supporting yourself and [the person with dementia] throughout this journey?” (e.g., participation in Ithaki’s activities, hiring a home help, better information about the condition)

2 Presentation of e-Health Technologies for Dementia Care

2.1 Familiarity with the various e-Health technologies used in dementia care:

- “Globally, e-Health technology (i.e., delivering health services digitally) is playing an increasingly important role in supporting people with dementia and their caregivers. In the context of Cyprus, I would like to hear about your personal experiences and knowledge about the use of these technological interventions in dementia care. To begin with, are you aware of specific interventions or e-Health tools that have been implemented to support people with dementia and their carers?”

2.2 Brief descriptions and indicative examples of three categories of e-Health technologies used in dementia care in the Netherlands:

- Category A – Safety and monitoring: (a) Sensors that identify the person in the home without cameras, study and learn the pattern of the person with dementia’s daily life, and then these activities are recorded online on a platform that can be accessed by caregivers and health professionals; (b) If a suspicious or dangerous change in behaviour occurs, the caregiver is informed immediately; (c) Ideal for people with dementia who live alone.
 - Category B – Communication: (a) Digital support of daily activities via a screen or robot, managed by the carer from a mobile or computer app; (b) The caregiver takes over what updates, reminders, and messages the person with dementia will receive and when; (c) Ideal for caregivers who are overloaded with personal commitments.
-

-
- Category C – Care coordination: (a) Care provided online, via laptop, tablet, or mobile phone; (b) Shared space where health professionals, caregivers, and people with dementia can interact, especially to serve daily challenges (e.g., help with food or pills); (c) Ideal for caregivers and people with dementia who live far from the city and from each other.
-

3 Discussion on e-Health Technologies for Dementia Care

3.1 Attitude towards e-Health technology for dementia care:

- “Based on the interventions presented, what is your overall impression of the use of e-Health technology for dementia care?” (e.g., “What feelings did you have when I presented these ideas to you?”)
 - “Now I would like you to tell me more specifically, for each of the technologies, which aspects or features of these technologies do you find most important and why?” (e.g., “Which functions or features do you find most useful in supporting the independence of your loved one with dementia?”)
-

3.2 Social norm towards e-Health technology for dementia care:

- “Based on your experience, how do you think people with dementia would react to the implementation of the first, second or third technology for dementia care?”
 - “What would (for you) other important people in your life think about the use of these technologies for dementia care?”
-

3.3 Personal norm towards e-Health technology for dementia care:

- “Which e-Health solution seemed most important to you and why?”
 - “Is there any technology from the options given that you would be least interested in exploring? If so, could you explain why?”
-

4 Summary

4.1 Round-up of the discussion:

- “Before we conclude the interview, is there any thought or important point you would like to share with me (that we haven't covered yet)?”
-