Designing, Implementing and Evaluating Assistive Technologies to Engage People with Dementia and their Caregivers

A practice-based approach to
explore the potential and impacts of
exergames to foster interaction, social participation
and well-being in private and institutional care contexts

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ABSTRACT

Increasing life expectancy and consistently low birth rates have led to a larger aging population, more individuals requiring care, and related phenomena such as dementia. Information and communications technology (ICT) may contribute to a better quality of life for older adults when enabling their health, safety, care, and social participation. Exergames are generally video games that involve different physical and cognitive exercises to encourage physical activity. Furthermore, aspects of gamification often support these exergames to foster new ways of engaging and stimulating individuals in interactive fitness. Indeed, studies have indicated that using exergames can result in improvements in individuals' fitness, adherence, and balance, irrespective of their ages. The goal of this thesis is to explore whether appropriately designed exergames could improve the social interaction, collaboration, and well-being of people with dementia (PwD) and their caregivers.

The thesis followed a practice-based design approach to develop a suite of exergames based on long-term engagement with PwD in different care settings and considered the relevant stakeholders' diverse levels of needs and demands, designed a tailorable suite of exergames, and investigated its appropriation. Throughout the research phase, we assessed the appropriation, individual and social experiences, and integration of the exergames into daily life across the different care settings; the system of games was continuously redesigned, refined, and extended to reflect the insights that arose from our observations of its use, as well as feedback from the PwD and their caregivers. This thesis thus addresses the following research questions: (1) What are the long-term impacts on the activities of daily living (ADL) for individuals living with dementia? (2) What are the social, institutional, and emotional experiences for their relatives and caregivers? (3) How are systems individually and socially appropriated and contextualized? Finally, (4) how should exergame-based activities be designed to positively affect individual resources while considering the social environment in dementia care?

Our results illustrate that besides the observed and reported impacts on physical activity and especially social interaction during and after exergame use, strengthened relationships and increased engagement were observed among PwD. These socio-emotional aspects were reported to encourage PwD in the long-term use of the system and motivate them to appropriate and engage with it. We noted that the grandchildren of PwD began to develop an interest in the

exergames and played them together regularly. People with dementia and their grandchildren also played the games together, and opportunities for relatives to follow the activities in their own social lives, such as reading books, meeting friends, and going out for walks, were thus created.

The findings indicate further specific advantages for the relevant stakeholders, which the system initiates within the social environments of PwD. In fact, the system was confirmed to destroy barriers and facilitate social connections for some participants. Particularly in day-care centers, participants were observed to develop a certain group dynamic and sense of interpersonal relationships while playing the games, which strengthened their collaboration, as well as their motivation to interact with and support one another. The social collaboration during group sessions often encouraged and helped them all and thus generated a cooperative, respectful, and motivating atmosphere. Relatives and professional caregivers reported having noticed the positive emotions, collaboration, and expressions that the PwD exhibited while using the system and that the games were a starting point for further discussions, even after the sessions. In addition, the studies conducted reveal that the appropriation and integration of the system depend only partly on the physical and cognitive benefits for PwD but especially on the social impacts and added value that their social care networks perceive. However, certain challenging aspects of using the exergames disclose some interesting insights for the community regarding how to improve the design in this area, covering matters such as malfunctions when interacting with the exergames, personal misapprehensions, and interpersonal frustrations.

This thesis analyzes and discusses the results of the underlying studies by focusing on the need for a design in dementia care that conceives more socially embedded innovations that can address the social actors and diverse experiences involved. We argue that these effects are fundamental to successfully integrating technologies in the complex environment of dementia care. This thesis therefore contributes to expanding the current discourse on Human-Computer Interaction (HCI) and dementia care by examining the impact of a suite of exergames that was designed to support the ADL of PwD and their caregivers.

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INTRODUCTION

Motivation

Social changes such as increasing life expectancy and consistently low birth rates have led to a rise in the number of older adults and therefore those in greater need of care compared to the rest of the population. Changing family structures in the form of one-person households, the rising shortage of skilled workers, the increased mobility and associated growing distance between parents and their children, and medical progress have posed an unprecedented problem for the existing health and care structures. As a result of aging societies, the risk of being affected by not only the need for long-term care but also dementia is increasing. The World Health Organization (WHO, 2017) estimates that more than 46.8 million individuals have Alzheimer's or a related form of dementia (WHO, 2017). Additionally, studies indicate that this number will continue to rise until 2050, when it will affect one in 85 individuals, most of whom will be living in developed countries (Brookmeyer et al., 2007). Several activities and interventions could positively affect managing everyday life around the challenges of dementia, as well as the progression of dementia itself. For example, physical and cognitive activity can reduce the risk of developing dementia and its progression (Eggermont, L. & Scherder, E., 2006; Ruan, 2015). Physical activity targets an improvement in not only physical ability but also cognitive resources, the scope for social interaction, and psychosocial health and well-being (Gajewski & Falkenstein, 2016; Peluso & Andrade, 2005).

Studies have confirmed that physical training in dementia can improve the mental health, cognitive performance (information processing and coordination), physical performance, and therefore daily competences of PwD (Blankevoort et al., 2010a; Hauer et al., 2012; Jia et al., 2019). Various methods can be used to support PwD and thus their quality of life while relieving their social environments. What seems to be a promising approach involves technologies that increase physical activity, cognitive resources, social participation, and well-being in PwD and their caregivers (Brankaert et al., 2019; Dove & Astell, 2017; Gibson et al., 2015; Lazar et al., 2018). Information and communications technology–based prevention and training activities—especially programs such as exergames, which are video games that involve different physical and cognitive exercises—may ease the access for older adults and individuals living with dementia, improve their physical and mental capabilities, and relieve related actors; however, few studies have utilized exergames as training measures. In this context, studies have demonstrated that exergames may stimulate the physical activity and fitness of older adults at home (Gschwind et al., 2015; Silveira et al., 2013; Vaziri et al., 2017a). In their study, Keogh et al. evidenced that the use of exergames improved physical reliability and physiological well-being in older adults (Keogh et al., 2014). Similarly, Schoene et al. illustrated that video game–based exercises helped to improve the physical and cognitive aspects of participants in the field of fall prevention (Schoene et al., 2013). Nonetheless, these results refer to older adults without dementia. A major challenge has therefore emerged in the appropriate and needs-oriented design and development of such innovative solutions that can be embedded in the everyday lives of PwD, as well as their relatives and professional caregivers. Moreover, few empirical studies have examined the potential and long-term impacts of using exergames to support PwD and their caregivers in coping with the challenges of social and daily life. A pressing need for more focused studies on HCI and computer-supported cooperative work (CSCW) that can inform the ongoing discourse on the design, research methods, and development of ICT-based systems such as exergames has thus evolved.

This thesis investigates the effects of an ICT-based training system for PwD and their caregivers, considers the fundamental individual impacts and social contexts of human-technology interaction in dementia, and presents implications, as well as lessons learned, to identify and explore possibilities for further research and development. A suite of exergames was developed to support PwD and their caregivers in coping with the challenges of daily living. Together with academic partners from the fields of sports science, sport gerontology, and nursing science, we continuously designed and tested the exergames and even the technical setup itself with PwD and their caregivers, using a participatory design approach in an established LivingLab near Siegen. On a conceptual level, the games integrated different ideas (activity, prevention, cognition, and creativity) based on established practical activities in care settings and evidence-based interventions from across those diverse academic disciplines for the first time. The underlying design objective was the provision of a suite of activities that can offer PwD support across their ADL, rather than single games with a united purpose. The following section presents the structure of this thesis.

Structure of the Thesis

This thesis includes three main sections: (1) the introduction, related work, and the concept of the study; (2) the key results; and (3) a summary of the findings, followed by the discussion. **Chapter 1** presents the motivation for and structure of this thesis. **Chapter 2** outlines the state of the art in the field of health- and care-related socio-demographics, introduces dementia as a social phenomenon, and establishes its impact on the individual and social lives of PwD and their social care networks. It also describes the state of the art in health technology development and exergames, as well as the research area of HCI and dementia. **Chapter 3** submits the contribution and research questions of this thesis, while **Chapter 4** provides the fundamental methodological framework, research settings, and research approach, as well as the exergames and technical setup that the research builds upon.

Chapters 5 to 8 present the main papers that have been published as conference or journal papers. **Chapter 5** elaborates on the first findings from the LivingLab study, which explored the potential for exergames to affect the social and daily lives of PwD and their caregivers. Qualitative data was collected over eight months, during which time the daily life integration and experiential aspects of the system were examined. These findings illustrate that the system enhanced social interaction, strengthened relationships, and improved the empowerment of PwD and their caregivers, allowing them to face daily challenges. **Chapter 6** focuses on the collaboration and social experiences that the exergames encouraged in the daycare group sessions, exploring the social experiences of 26 PwD and their caregivers in a 16-month design case study. The results illustrate that collaboration and cooperation among the parties involved (PwD, relatives, caregivers, and researchers) increased after using the system for an extended time. The study revealed that the exergames-based system triggered positive and negative social experiences. This chapter also provides implications for the future design of similar systems and their potential to further encourage collaboration and cooperation among PwD and their caregivers.

Chapter 7 presents the outcomes of a case study that specifically focused on the evaluation of a music-based exergame for PwD and their caregivers. The developed interactive music-based exergame combines two promising domains: physical activity and music-based interventions that can effect movement, creativity, and meaningful stimulation. The results indicate a valuable impact of music-based interventions, which provide positive psychological, social, and physical effects in day-care and domestic settings. Significantly, the music-based exergame reconstructed the memories and enhanced the social engagement of PwD within their families, with their professional caregivers, and with various external parties. **Chapter 8** investigates the appropriation of caregivers in engaging PwD with the exergames, focusing on the long-term role of caregivers in appropriating the exergame-based system into their lives and the challenging daily lives of PwD. In addition, this chapter presents the outcomes of the final evaluation study, in which the everyday behavior and interactions of 53 PwD and 25 caregivers were studied qualitatively, concentrating on the role of caregivers in integrating the system into everyone’s daily routines. The results indicate that the successful appropriation of the exergame depends on not only the physical, cognitive, and social benefits for PwD but also the added value that their social care networks perceive. This chapter also discusses the need for design in dementia to conceive more socially embedded innovations that can address the social actors involved and thus contribute to practical solutions for professional and informal dementia care.

Chapter 9 presents summarized findings from across the different papers; **Chapter 10** then discusses the case studies in view of the research questions. This thesis offers insights that could help to support designers and researchers working from various perspectives, those who seek to distribute a broader set of possible engagements with PwD, and those who want to provide engagements for other stakeholders who share some of the same characteristics. Moreover, it presents lessons learned for the future design of technologies, particularly exergames, to support the complex individual and social circumstances and heterogeneity of PwD and their social environments. **Chapter 11** concludes the thesis and highlights its contribution to the field of HCI.

Disclaimer

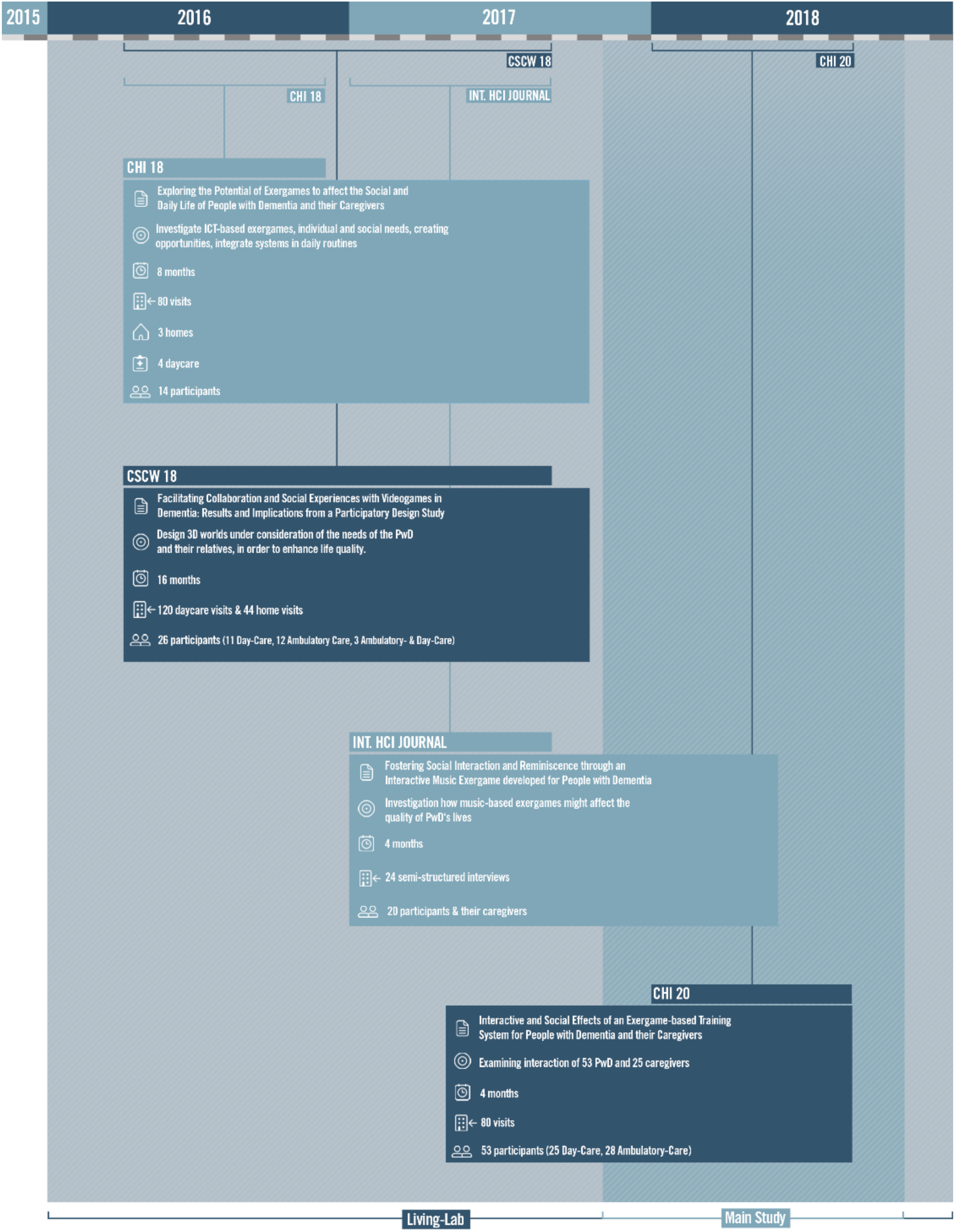
The following summarizes the published and submitted articles, which will be presented in **Chapter 5 to 8** of this thesis.

Exploring the Potential of Exergames to affect the Social and Daily Life of People with Dementia and their Caregivers (Chapter 5; Unbehaun et al., 2018f**):**
This work has been published as a conference paper in the Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems:
Unbehaun D., Vaziri D.D., Aal K., Wieching R., Tolmie P., Wulf V. Exploring the Potential of Exergames to affect the Social and Daily Life of People with Dementia and their Caregivers. In Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems (CHI '18). ACM, New York, NY, USA, Paper 62, 15 pages. DOI: 10.1145/3173574.3173636

Facilitating Collaboration and Social Experiences with Videogames in Dementia: Results and Implications from a Participatory Design Case Study (Chapter 6; Unbehaun et al., 2018a**):**
This work has been published as a journal paper in International Journal of Computer Support Collaborative Work:
Unbehaun D., Aal K., Vaziri D.D., Wieching R., Tolmie P., Wulf V. Facilitating Collaboration and Social Experiences with Videogames in Dementia: Results and Implications from a Participatory Design Study. Proc. ACM Hum.-Comput. Interact. 2, CSCW, Article 175 (November 2018), 23 pages. DOI: 10.1145/3274444

Notes of Memories: Fostering Social Interaction, Activity and Reminiscence through an Interactive Music Exergame developed for and with People with Dementia and their Caregivers (Chapter 7; Unbehaun et al., 2020**):**
This chapter has been published as a journal paper in the International Journal of Human-Computer Interaction:
Unbehaun D., Taugerbeck S., Aal K., Vaziri D.D., Lehmann J., Wieching R., Tolmie P., Wulf V.. Notes of Memories: Fostering Social Interaction, Activity and Reminiscence through an Interactive Music Exergame developed for People with Dementia and their Caregivers. In International Journal of Human-Computer Interaction (2020). DOI: 10.1080/07370024.2020.1746910

Social Technology Appropriation in Dementia: Investigating the Role of Caregivers in engaging People with Dementia with a Videogame-based Training System (Chapter 8; Unbehaun et al., 2020a**):**
This chapter has been published as a conference paper in the Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems:
Unbehaun D., Aal K., Vaziri D.D., Tolmie P., Wieching R., Randall D., Wulf V . Social Technology Appropriation in Dementia: Investigating the Role of Caregivers in engaging People with Dementia with a Videogame-based Training System. In: In Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems (CHI '20). DOI:10.1145/3313831.3376648



CHI 18

Exploring the Potential of Exergames to affect the Social and Daily Life of People with Dementia and their Caregivers

Investigate ICT-based exergames, individual and social needs, creating opportunities, integrate systems in daily routines

8 months

80 visits

3 homes

4 daycare

14 participants

CSCW 18

Facilitating Collaboration and Social Experiences with Videogames in Dementia: Results and Implications from a Participatory Design Study

Design 3D worlds under consideration of the needs of the PwD and their relatives, in order to enhance life quality.

16 months

120 daycare visits & 44 home visits

26 participants (11 Day-Care, 12 Ambulatory Care, 3 Ambulatory- & Day-Care)

INT. HCI JOURNAL

Fostering Social Interaction and Reminiscence through an Interactive Music Exergame developed for People with Dementia

Investigation how music-based exergames might affect the quality of PwD's lives

4 months

24 semi-structured interviews

20 participants & their caregivers

CHI 20

Interactive and Social Effects of an Exergame-based Training System for People with Dementia and their Caregivers

Examining interaction of 53 PwD and 25 caregivers

4 months

80 visits

53 participants (25 Day-Care, 28 Ambulatory-Care)

Figure 1: Publication History and Project Trajectory

STATE OF THE ART

Demographic Transition, Aging, and Dementia

Demographics in Aging Societies

Demographic change in Europe and especially Germany is expected to become a larger societal challenge in the future than it has been thus far. While life expectancy, consistently low birth rates, and the number of older individuals have been increasing, the proportion of skilled workers and the German population have been decreasing drastically (DeStatis, 2018). The increased number of older adults and thus individuals needing care, as well as simultaneous changes in family structures (the transition to one-person households and the latest migration patterns of younger individuals), have led to the lapse of previous insurance and a solidarity-based social system. Nevertheless, today's society bears a great responsibility for and moral obligation toward tomorrow's individuals requiring care and medical services. The anticipated situation in Germany indicates critical reflection on the care system used so far, innovative methods related to the forms and structures of care, further development of technical assistance systems, and increased funding for research and development in the health, care, and medical domains. The demographic and social changes represent a common challenge—for families and society at large, science, the economy and especially the labor market, social security systems, and politics (Klingholz, 2016). Although age and increasing life expectancy are not synonymous with illness and the need for long-term care, a correlation between the aging of the population and the increasing number of individuals needing long-term care still exists. The number of individuals requiring care in Germany will rise from 3.5 to 5.3 million by 2050 (Ehrentraut et al., 2019). Additionally, those who need long-term care are cared for mainly at home (DeStatis, 2018), which corresponds to older individuals' desire to live in their familiar surroundings as long as possible (Statista, 2019). Providing this care is the responsibility of society as a whole; however, the challenges and related pressure for individuals needing care, caring relatives, professional caregivers, and providers of health and care services remain intensive.

Dementia and Its Individual and Social Impacts

In 2015, Alzheimer's Disease International stated that "over 46 million people live with dementia worldwide, more than the population of Spain." Furthermore, "this number is estimated to increase to 131.5 million by 2050" (World Alzheimer Report, 2015). As a result of the demographic transition and aging societies, the need for long-term care is increasing. Dementia is one of the most common phenomena of old age and can be found in almost every second individual requiring long-term care in outpatient care (Statista, 2016). This disease is considered one of the main reasons for leaving one's domestic environment and social surroundings. An estimated 1.3 million individuals currently live with dementia; according to forecasts in Germany, 2 million individuals will be living with dementia in 2030, and as many as 2.6 million in 2050 (Sütterlin et al., 2011:5). The anticipated situation for seniors, those needing long-term care, and PwD necessitates a reorientation of established care structures and the reallocation of available resources, as well as innovative possibilities for the realization of self-determined and dignified aging. Dementia involves various symptoms and impairments that prevent individuals from performing their everyday activities as usual. These include impairments of memory and other brain functions, such as orientation, language, and the ability to learn, which are gradually and irretrievably lost (Sonntag & Reibnitz, 2014).

A distinction is made between primary and secondary dementia, with the former (Alzheimer's dementia) being the much more common form since it occurs in 90% of all cases. Secondary dementia includes neurodegenerative and vascular dementias, as well as mixed forms, such as Lewy body dementia (Alzheimer's Association, 2020). Vascular dementia characterizes the clinical picture of dementia based on various cerebral ischemia constellations and is the second most frequent cause of dementia. It is often difficult to clinically identify any given form as both manifestations are subject to vascular risk factors in their course (Adler, 2009). From a biomedical perspective, dementia is a clinical condition whose initial symptoms can include reduced memory performance and disturbances in one's sense of time and space. Temporal disorientation, which generally occurs before spatial disorientation, manifests above all in everyday behavior. Individuals with early-stage dementia often forget to keep appointments and agreements, have a disturbed day-night rhythm, or lose their ability to estimate time; in addition, PwD realize the loss of their abilities, which often leads to depressive disorders and social isolation (Radenbach, 2014:21). In the middle stage of dementia, the dimensions of disorientation increase even further. Individuals endure situational and local disorientation, as well as temporal disorientation. Local disorientation initially manifests in forgetting one's place of birth or current address, for instance, and can lead to forgetting objects that have just been removed. Moreover, individuals living with dementia can no longer provide sufficient information about themselves, make mistakes in sentence structure, and confuse individual words. Repeated questions can arise within a short amount of time, and the function of objects can be confused. Individuals living with dementia can recognize these changes but can no longer reflect on them. In an average stage, they cannot master everyday actions and activities alone. In the latest stage, these individuals lose control of motoric movements such as walking, standing, and sitting and develop an increased muscle tone, which can lead to contractures, immobility, and bedriddenness.

Dementia can be considered a medically or biologically oriented clinical condition; nevertheless, from a clinical perspective, it is defined as a dynamic neurodegenerative cerebral disorder that involves the weakening and progressive decline of first cognitive and then physical capacity, leading to disability and death (WHO, 2019). The term “dementia” refers to several manifestations that can have multiple causes (McCabe, 2008). Alzheimer’s dementia is the most well-known form of dementia in the Western world, even though the proportions of various forms of dementia can fluctuate in different parts of the world (Jacques & Jackson, 2000). From a social perspective, dementia and its impacts correspond to the social construction of dementia; the (treatment) context; and the impacts on familial connections, relationships, and caregiving structures (Lyman, 1989). The biomedical definition was challenged in 1997 when Kitwood suggested a more holistic approach to dementia, defining it as the interplay between neurological damage and psychosocial environment (McCabe, 2008).Indeed, a move toward a less medical and more holistic view of dementia has begun to influence public perceptions and academic practices in the field of HCI (Brankaert et al., 2019; Houben et al., 2019; Kitwood, 1997; Lazar et al., 2017a, 2018; Morrissey et al., 2017a; Morrissey & McCarthy, 2015; Welsh et al., 2018). Dementia negatively affects not only individuals’ physical welfare but also their social lives and relationships with others (WHO, 2019). It also impacts families and social and (health) care structures (Brodaty & Donkin, 2009; Coon & Evans, 2009; Schulz & Sherwood, 2008). Family members disregard their needs and emotions to care for their loved ones, resulting in emotionally and physically exhausted caregivers. Additionally, caregivers often need to reduce their social contacts due to the time and effort required for care behavioral changes and are therefore confronted with emotional and organizational challenges they cannot manage (Sörensen & Conwell, 2011; Sütterlin et al., 2011). While a paradigm change concerning the well-being of PwD has occurred, deterministic opinions of dementia should vanish with time.

Relatives of individuals requiring long-term care are especially exposed to intense physical, psychological, and financial stress (Schorch et al., 2016). The organization of care activities restricts family members, and the social care network can inevitably initiate a reorientation of daily structures and lifestyles in the lives of PwD and their caregivers (Chassioti, 2014). Relatives must contend with complicated administrative documents, negotiate with care insurance funds regarding the need for care of the person concerned, ensure and document adequate care, and apply for any medical or technical aids. Disturbed communication between the involved actors can cause severe losses in the family's internal and external relationships. This phenomenon is associated with the terms "hidden patient" and "caregiver overload" (Bindel & Pantel, 2012:2). From a medical perspective, relatives of PwD have an increased risk of cardiovascular events, a weakened immune system, and decreased wound healing due to chronic stress. Many households also suffer financial cuts, as full-time gainful employment is usually no longer possible.

While the medical aspects of dementia have been the subject of research for some time, the social aspects have recently begun to receive more prominence as the symptoms can limit PwD in their everyday lives. Different measures can slow and restrict the loss of these individuals' cognitive and physical abilities. In fact, numerous medical and non-medical treatments aim to maintain practical skills for as long as possible, which can help PwD and their families to cope with the challenges of daily life. Adequate responses, communication, and interaction with PwD are therefore essential to maintaining the coherence of their social environments. Kitwood's person-centered care approach (Kitwood, 2013) focuses on the humanity of PwD, arguing that they should be seen as individuals with needs rather than judged on superficial factors. Dementia not only restricts individual physical resources but also affects the social lives of PwD and their relationships with those around them. Despite the paradigm shift regarding PwD and their well-being in academic practices, especially in the field of HCI, more integrative research and interdisciplinary collaboration are needed to face the deterministic and negative view in the development of ICT in dementia care. Such an integrative research approach with combined methods could be valuable in understanding contradictions between quantitative and qualitative results.

Physical Activity and Training in Dementia

Several studies have verified that physical activity and a vital lifestyle have a positive effect on the risk of developing Alzheimer's and other forms of dementia. In their 2013 study, DeFina et al. discovered that a high fitness level can protect against not only the dangers of stroke and diabetes mellitus but also dementia in middle age (DeFina et al., 2013). Ngandu et al. came to similar conclusions in their 2015 geriatric intervention study on the prevention of cognitive impairments and ability disorders, in which PwD were treated at six study centers in Finland for more than two years. The researchers demonstrated significant positive intervention effects in the general and secondary cognitive domains (executive functions and processing speed), as well as in other secondary areas (body mass index, dietary habits, and physical activity). The findings from this long-term large randomized controlled trial confirm that a versatile intervention program can maintain or even improve the cognitive functions of older individuals (Ngandu et al., 2015).

Many studies have also considered the effects of exercise on dementia. These studies have indicated that exercise programs that focus on training motor skills to support common movements such as standing, dressing, and balancing are particularly suitable for PwD and have positive effects on physical and cognitive functionality (Kunz et al., 2014). In 2010, Blankevoort et al. investigated the effects of physical activity on strength, balance, mobility, and the performance of daily activities in older PwD; in a systematic review of 10 randomized studies and six case studies with a total of 642 participants, they found that physical activity is beneficial in all stages of dementia. A multicomponent intervention in the form of endurance, strength, and balance exercises led to greater improvements in walking speed, functional mobility, and balance than strength training alone. Only four of the 16 studies assessed the activities of everyday life. These four studies included three with high training intensity and frequency, which concluded that improvements occurred in the individual activities of daily living. In most cases, the greatest improvements in physical functioning were observed after sports and exercise programs with high training intensity and frequency. Based on their data, Blankevoort et al. concluded that the greatest improvements followed programs of at least 12 weeks and a regularity of three times a week for 45–60 minutes. Furthermore, improvements were observed in all stages of dementia (Blankevoort et al., 2010).

In 2004, Heyn et al. examined the effects of exercise training on older individuals with cognitive impairments and dementia in 29 randomized control studies and one controlled study. Overall, information from 2,020 participants was used, with the result that sports and exercise programs increased fitness, physical and cognitive function, and positive behavior in the target group. The exercises of most of the primary studies (n = 17) focused on walking and running training (mobility training) or combined walking and running training measures with various isotonic exercises. The contents of the other measures were structured differently: Three studies used stool exercises, while another three studies used an aerobic dance format. Two studies used exercise programs based on weight training. Finally, two domestic studies included stationary cycling combined with other exercises. The average age of the participants was 80 ± 6.1 years, and the range was 66–91 years. In addition, 72% of the participants were female and 38% male. Regarding physical fitness, the study found that exercise training had a significant positive effect on physical performance. Indeed, 487 cognitively impaired older adults participating in strength training programs had significantly improved strength compared to the 492 cognitively impaired older adults in the control group. The results of this study also revealed moderate to strong positive effects in the intervention group in the areas of flexibility, cognition, and physical performance (Heyn et al., 2004).

In their 2012 systemic review of 20 randomized controlled trials and a total of 575 participants, Pitkälä et al. determined that exercise has positive effects on mobility. Six of these studies found positive effects on functional limitations, while 16 demonstrated the positive effects of sports and exercise programs on physical functioning and functional limitations (Kunz et al., 2014:116). Hess et al.'s 2014 systematic review of 14 studies and a total of 1,056 participants confirmed that physical functioning in the respective intervention groups improved significantly, and the participants became more active. Through their analysis, they concluded that physical activity in the form of sports and exercise programs can be an effective therapy and an appropriate intervention tool for individuals with cognitive impairments and PwD (Hess et al., 2014).

In Graessel et al.'s 2011 randomized controlled trial, 98 individuals diagnosed with dementia were examined in five nursing homes over 12 months. The study contains three unimodal therapeutic components, including motor skills, everyday practice, and cognition. The entire study setup was combined with spiritual attunement. The research proposed that PwD who participated in the multimodal nondrug intervention exhibited better cognitive performance and fewer restrictions regarding everyday abilities after 12 months. The study interventions were conducted at the nursing homes for two hours six times a week. Following the 12 months, the study interventions had a significant positive effect on the cognitive and practical abilities of the residents in the intervention group compared to the control group in PwD (Graessel et al., 2011). In their article "On the Influence of Sports Training on Memory and Attention Performance in Older Persons and Persons with Alzheimer's Disease," Eichberg et al. report that in a 2008 intervention study conducted with 33 PwD and 61 cognitively healthy individuals that focused on strength training content, sports training improved the information processing speed and concentration performance of cognitively healthy and demented individuals (Eichberg, 2008). Moreover, a 2008 study by Brach et al. investigated the effects of strength training on motor functions and physical performance in PwD; eight women and 24 men with early- and mid-stage dementia and an average age of 71 years were observed in a 12-week strength training program. The test and evaluation were based on isometric strength tests of the lower extremities, such as stand-up tests, balance tests, and the measurement of reaction speed. Compared to the control group, the intervention group revealed improvements in motor function and performance in almost all tests (Brach et al., 2008).

Creative and Social Interventions in Dementia

In addition to physical activity and training, creative activities, music, and shared recollections could have positive effects on PwD. Art therapy, for instance, can benefit sociability, improve self-esteem, and provide meaningful stimulation (Hannemann, 2006; Logsdon et al., 2007; McDermott et al., 2014). Art therapy can also reduce depression, a lack of life perspective, and isolation in PwD while increasing their ability to make decisions and their overall sense of hope (Hannemann, 2006; Sarkamo et al., 2014; Schmitt & Frölich, 2007). Allan and Killick highlight the importance of communication and understanding its different facets—not only verbal communication but also emotional expressions, as with dementia, these can change over time (Allan & Killick, 2010). Participation in these activities must be seen in a nuanced way, and Morrissey et al. argue that experience-centered design is needed to produce and further enhance these enriching experiences (Morrissey et al., 2016a).

A vast repertoire of non-medicinal approaches to interacting with PwD come from various theoretical backgrounds, with music being one such approach that has become increasingly established. Phinney et al. stress the significance of meaningful activities that largely depend on involvement and enjoyment, thus providing PwD with a sense of connection and belonging and maintaining their sense of autonomy and personal identity (Phinney et al., 2007). Music accompanies individuals through different stages of their lives and transcends verbal communication, often working most forcefully at an emotional level (Wall & Duffy, 2010). The uses to which music might be put are almost as diverse as the biographies of the PwD themselves. When examining the potential of music therapy to aid cognition in the context of

Alzheimer’s, Fang et al. (2017) investigated the literature for different techniques, clinical trials, and possible mechanisms, finding that music-based activities can reduce cognitive decline, especially regarding autobiographical and episodic memories, psychomotor speed, executive functions, and global cognition. They therefore recommended the earliest possible use of music therapy as an intervention for dementia (Fang et al., 2017). Music has several potential uses when interacting with PwD: it can support an individual’s physical, emotional, mental, social, and cognitive needs by restoring, maintaining, and promoting mental, physical, and emotional well-being. As a transcendental language, musical activity represents a way for potentially accessing PwD, even at an advanced stage. It can strengthen a sense of identity and self-confidence, stimulate communication processes, and counteract isolation. For our work, these prior studies provided an important background when selecting appropriate study sites, deciding the degree of active participation needed, choosing musical material, and assessing the degree of engagement and collaboration with PwD, their families, and caregivers required.

In summary, a wide range of activities can positively affect living with dementia and its individual and social consequences. Additionally, different treatments can decelerate the progress of cognitive difficulty and the loss of common capabilities (Colcombe & Kramer, 2003). Exercise programs have proven to be promising since they target not only the symptoms of dementia but also other risk factors. Studies have indicated that exercises can improve physical abilities and hence the everyday capabilities of PwD (Kemoun et al., 2010). Outside of physical activity, treatments also seek to involve PwD in other pursuits such as creative activities (crafts and drawing), music therapy (singing, listening, and dancing), and biography-oriented activities (re-enabling former hobbies and interests). These activities have been found to positively affect individual mood, social-emotional behavior, and communication skills, thus improving psychosocial well-being. Art and music therapy can improve not only the memory but also the happiness of PwD. It can reduce depression, a lack of life perspective, and isolation as well all while increasing their ability to make decisions and their overall sense of hope (Hannemann, 2006; Sarkamo et al., 2014; Schmitt & Frölich, 2007). Again, participation in these activities must be seen in a nuanced way, and Morrissey et al. argue that experience-centered design is needed to produce and further enhance these enriching experiences (Morrissey et al., 2016a). Given all this experiences and knowledge, technological solutions that seek to support PwD and their caregivers in everyday life must consider not only physical and cognitive activities and related performance but also mutual and meaningful experiences, alongside aspects of the routine activities present in their lives.

Designing and Developing Technology in Aging and Dementia

The work presented in this thesis adopts approaches from specific fields of HCI to obtain a detailed understanding of the practice-oriented and experience-centered design, development, and evaluation of the overall system.

Technology in Aging and Dementia

Due to the aforementioned demographic change with all its economic and sociodemographic consequences, the future situation is predicted to result in more individuals not receiving appropriate professional care and social support. Regarding the differentiated approaches and critical scientific discourses in the field of social sciences and technology, older users are often associated with negative societal assumptions about aging and considered to be limited by physical and cognitive deterioration, as well as slow at performing with technology, and thus experience social isolation and a loss of independence and competence to manage their daily lives (Vines et al., 2015). Technical assistive systems for individuals needing care, especially PwD, could offer tailored and needs-based therapy concepts and activities. Important and forward-looking questions address how such socio-technical assistance systems will look and what kind of support will be offered for PwD and their families. For instance, how can a socio-technical perspective establish across different research domains, and how will care scenarios and practices develop further? What role can technology have in this scenario, and how can it be integrated into individual and social lives, care networks, and practices? To what extent can a technical implementation consider and suit the sensitive and vulnerable circumstances in dementia care? Inspired by the prior arguments of Vines et al. (2015), we ask whether the ways in which dementia and the related development of IT in multiple ongoing disciplines are framed, articulated, and understood as an interdisciplinary research challenge in the field of HCI and based on the predominating biomedical view of dementia is limiting how we design and evaluate technology for and with PwD.

To approach these questions, in the following section, we provide an overview of the state of the art in research and technology regarding ICT in the context of dementia in the following section. Several technical solutions for dementia are available on the market; some are currently available and differ considerably according to the respective field of application and degree of product readiness. The most common solutions in the context of dementia concern the fields of electronics, microsystems, and software technology. The current research situation is characterized by many studies and funding programs that have determined to develop ICT to support PwD and their caregivers. The technologies can be divided into six categories: (1) virtual companions and navigation assistance, which enable support in navigation, day structuring, and communication; (2) therapy and companion robots, which are used for emotional stimulation and promoting social interaction; (3) support robots, which help individuals with logistical and domestic activities (one form, so-called prompting systems, can help in the form of linguistic or visual hints for day structuring); (4) mobilization by movement trainers (serious games, exergames, and health games), which support and stimulate one's health and quality of life by the physical activation and training of elementary motor functions; (5) systems that can activate emotionally and cognitively through memory exercises, creative stimulation, and biography work, which help PwD to not lose touch with their environments; and (6) activity monitoring that enables the creation of activity profiles using discrete sensor technology and anomalies to be registered and intervened accordingly (Schultz et al., 2014).

Human-Computer Interaction in the Context of Dementia Care

Over the past decade, research and development in the field of HCI and dementia care has provided technological models and research results that offer novel insights in all six categories mentioned above, such as social participation, personal autonomy, and the quality of life of older adults and PwD (Mokhtari et al., 2015; Müller, 2014; Müller et al., 2015; Pinto-Bruno et al., 2017a; Wan, L., Müller, C., Wulf, V., Randall, D., 2014). In the context of PwD, assistive technologies for the smart home, telecare, and low-level technologies are considered the most accessible assistive technologies on the public market. Furthermore, assistive technologies for PwD and their families are specifically designed to support the daily activities of PwD, for safety monitoring and as a memory aid, to prevent social isolation and facilitate everyday life (Lorenz et al., 2019; Martínez-Alcalá et al., 2016). The HCI-based literature concerning PwD has grown in recent years and covers topics that range from methodological approaches (Brankaert, 2016; Brankaert et al., 2019; Hendriks et al., 2014; Lazar et al., 2017; Morrissey et al., 2017), music and artifact development (Benveniste et al., 2012; Lazar et al., 2017; Morrissey et al., 2016b), exergames (Colombo et al., 2012; Unbehaun et al., 2018b, 2018d), and the use of art and design processes that focus on reciprocity (Kenning, 2018). These topics emphasize using (creative) engagement to articulate personality, with technology cast in a supporting role. In *Addressing the Subtleties in Dementia Care: Pre-study & Evaluation of a GPS Monitoring System*, Müller et al. present a user-centered development for a GPS-based monitoring system to be used in three different environments of dementia care: institutional care at a care home, institutional care at a hospital, and familial care at home (Müller et al., 2014). The study, which consists of a full design process, including the qualitative-empirical pre-study, the prototyping process, and the evaluation of the long-term appropriation processes of the stable models, addresses the problem of individuals with late-stage dementia wandering. While the developed model proved to have a positive impact on the experiences of PwD, their families (reducing anxiety among family members), and especially professional caregivers, who profited from a greatly reduced search area, some minor problems emerged: Interviewees reported a dislike of the tracker size, preferring smaller and known artifacts such as thin bracelets. In addition, the solution must be easily usable, even by older individuals and those less familiar with IT. In the study, older care home staff members had difficulties managing the system; above all, they stressed the need for flexible, creative, and practical solutions, adapting to the heterogeneity and complexity of caregiving contexts, as well as different users' needs in each specific context. Assistive tools must therefore consider the patient's condition, organizational and family routines, and the different moral commitments of the parties involved, as well as the consequential but constantly renegotiated care philosophies. Moreover, "solutions must allow tailoring to meet these conditions" (Wan, L., Müller, C., Wulf, V., Randall, D., 2014).

Numerous studies have also focused on enhancing or replacing the cognitive skills that erode over the course of an individual's dementia. Here, technology intends to help PwD connect with their environments. An example of such an intervention is Ticket to Talk, which facilitates the exchange of personal memories and intergenerational conversation (Welsh et al., 2018). Information communications technology can also deliver experiences that are no longer attainable in the real world. For instance, virtual reality environments offer a creative medium for comfortable and enriching experiences that can promote and improve the quality of life of PwD (Hodge et al., 2018). A significant outcome of many of these interventions is that they seek to involve PwD and other stakeholders in the design process (Brankaert, 2016; Unbehaun et al., 2018b). However, despite the highly principled ethos attached to these approaches, the interventions are often short-lived and framed by project timelines. The successful integration of these technologies over time depends less on the efforts of researchers than how the technologies are oriented to and promoted by caregivers.

Müller et al. have presented several empirical studies that were conducted in the context of developing a GPS locating system for individuals with dementia in Germany. In their study titled *Dealing with Wandering: A Case Study on Caregivers' Attitudes towards Privacy*, they reflect on the use of location-based systems (LBS) and how family and professional caregivers cope with wandering behavior, which is often a challenge for all actors involved (Müller et al., 2010). Reporting on the challenges of familial caregiving, Müller et al. observed that the caregiver often comes to the point of giving him- or herself up fully and seeing no personal space for rest . Concerning PwD, Müller et al. recognize that "for people in early stadiums [of dementia] where the system could provide a real enhancement of personal freedom and safety, people are often not open to look for suchlike help systems." Additionally, "caregivers of demented persons at home are elder people who have only low or no affinity to new media and ICT." Technology design and development must therefore consider several aspects from the professional caregivers' perspective, including the well-being and burden of demented patients, the degree of dementia and disorientation of PwD, the responsibilities of caregivers, the workload of caregivers, communicative strategies, legal and gender aspects, and the relationships between professional caregivers. Technology, in its functionalities, should thus consider the various contexts, strategies, and conditions of individual methods of coping with the individual and social context of PwD and their caregiving networks (Müller et al., 2010).

A growing body of work focuses on the relationship between HCI, music- and fitness-based activities (Biehl et al., 2006; Hartnett et al., 2006), and rehabilitation (Music & Murray-Smith, 2010). Some work also explores the relationship between music, auditory cues, and cognition (HCI Korea [Conference] et al., 2014). The most pertinent music-related literature in HCI, however, focuses directly on how music might contribute to therapy for PwD. This literature generally recognizes the potential benefits of using music with PwD. In fact, several studies suggest that passive music consumption and more active participation in the form of singing and dancing currently affect the lives of PwD in care homes (Morrissey & McCarthy, 2015). Some studies thus focus on providing smartphone-based applications to identify the music preferences of PwD and delivering filter-based recommendations based on this information (Stoeckle & Freund, 2016). Others recognize the difficulty PwD may have with conventional interfaces and offer distinctive ones that can handle the playback of music more effectively (Seymour et al., 2017). In a more active vein, some research has developed interfaces that might enable PwD to engage in creative music-making and musical performance. Riley, for instance, presents a creative use for touchscreens, while Favilla and Pedell extend this to touchscreen-based collaborative music-making for PwD (Riley, 2007; Favilla & Pedell, 2013). Drawing upon McCarthy and Wright's (2015) arguments about participation in experience-centered design, Morrissey et al. suggest using technology to support active music sessions in care homes with physical percussion instruments and props (Morrissey et al., 2016b). Some research notes that music therapists are becoming a scarce resource as the number of PwD grows and suggests ways that technology might support the remote provision of music therapy (Kosugi et al., 2013). Of particular note is an interactive music game that Tsiakis et al. specifically designed to improve the attention levels of PwD (Tsiakas et al., 2016). Here, a robot plays four songs and asks PwD to name them; it assesses the performance of the players and modulates the level of difficulty accordingly. This game is currently only in the design stage and has not been implemented. It was also founded solely on the music therapy literature rather than being grounded in specific studies with PwD.

Serious games and exergames are game applications that surpass pure gaming by combining information, skills, and knowledge entertainingly. For this purpose, different physical or cognitive exercises, computer games, and new technology is combined with a gamification approach into ICT and applied to a broad spectrum of application domains, such as training, education, sports, and health. Video games that focus especially on involving physical exercise in a virtual game environment are called exergames. Exergames have become increasingly visible in the field of HCI and health prevention and the support of physical activity in older adults in recent years (Douglass-Bonner & Potts, 2013; Siriaraya & Ang, 2014; Smeddinck et al., 2015a; Vaziri et al., 2017b). Advantages of exergames include the entertaining aspects of a video game that encourage users to train physical abilities and cognitive skills simultaneously. Exergame systems can include controllers with built-in sensors, such as the Nintendo Wii; pressure sensors, such as the Nintendo Wii Balance Board; and camera systems, such as the Microsoft Kinect or the Sony Playstation Eyetoy, which are controlled by gestures. An example application for exergames is the interactive TV system iStoppFalls, based on Microsoft Kinect, used to prevent falls in older individuals (Marston et al., 2015; Ogonowski et al., 2016a). Adapting to new information and exercising can lead to positive effects in learning and memory. Exergames in dementia care that combine physical and cognitive objectives could reequip PwD with capabilities and skills that facilitate social interaction and collaboration and thus help to ameliorate depression, anxiety, and stress (Férnandez-Calvo B., Rodriguez-Pérez R., Contador I., Rubio-Santorum A., Ramos F., 2011; Lazar et al., 2017b; Weybright E., Dattilo J., Rusch F., 2010). Padala et al. even found that exergaming can have a positive effect on the balance and gait of individuals with Alzheimer's (Padala et al., 2012). Exergames and cognitive serious games can also positively influence individuals on a social and emotional level, reducing depression and stimulating interaction. Yamaguchi et al. examined the effects of sports video games in a fixed care setting (Yamaguchi et al., 2011) and observed improvements in emotional and social health in situations of cognitive impairment, indicating the value of further research in this area. Robert et al. have therefore argued that serious games could be useful instruments for interaction between professional nurses and patients with cognitive limitations and have strongly advocated intensified collaboration between the relevant disciplines (Robert et al., 2014a).

Reflecting on Technology Design and Evaluation for Older Adults and in the Context of Dementia

As Vaziri states, the older adult population is heterogeneous, and the understanding of their perspectives on health, quality of life, and technology use may be complex (Vaziri, 2018). Approaching the ambitious aim of designing appropriate ICT for older adults in the context of dementia, utilizing qualitative and quantitative methods, could therefore enable the investigation of a wider range of subtle details, providing a more detailed and complete picture of older adults' practices, attitudes, perspectives, and relations with their social environments (Brannen, 2005; Green et al., 2015; Vaziri, 2018). To design and develop innovations that meet the practical demands of more than single users, researchers should use qualitative research methods to evaluate the diverse spectrum of the expectations and needs of users and stakeholders. Concerning participatory design as it was originally introduced in Scandinavia in the 1980s, where it was articulated related to the workplace democracy movement, the involvement of users is of particular importance as it facilitates close cooperation and interaction between stakeholders (Clement & Van den Besselaar, 1993). Participatory design can be defined as a

> democratic process for design (social and technological) of systems involving human work, based on the argument that users should be involved in designs they will be using and that all stakeholders, including and especially users, have equal input into interaction design. (Muller & Kuhn, 1993)

The method of participatory design therefore focuses on considering and understanding end users' knowledge so that they can actively participate in the design and development processes and thus conceive new solutions (Simonsen & Robertson, 2013). This participatory method can offer users a say in the design process without their knowing (or understanding in the context of dementia) the language of professional development, technological design, and various evaluation mismeasurements. When using the participatory design method, it is crucial that the users are fully involved in the design activities and that the resulting concepts and models are tested and evaluated in everyday environments under everyday conditions (Clemensen et al., 2017). The participatory research and development process is extended by the early assessment of user needs and the corresponding usage behavior in the everyday context. This step offers the advantage that context-specific usage problems and any unintended usage patterns can be detected at an early stage and that these findings can flow directly into the evaluation and thus enable the timely improvement and further development of the ICT-based application. This methodological approach aims for an improved understanding of the context, the development of demand-oriented end user models, the permanent context-relevant evaluation, and the development of concepts through discourse with users, developers, and researchers (Hartson, 2018; Kushniruk & Nøhr, 2016).

When it comes to designing for and with PwD, while individual circumstances matter, the social context must be considered as well (Hendriks, Truyen, & Duval, 2013). Depending on their states of dementia, PwD may not be able to communicate their emotions fully, so relatives or caregivers may need to serve as intermediaries, though it can be difficult for even relatives to accurately convey their needs. Bouchard et al. recommend developing appropriate interaction mechanisms for cognitively impaired individuals (Bouchard et al., 2012), and in the context of developing serious games, the design and exercises must be easily adapted to the cognitive abilities of the target group (Robert et al., 2014). To adequately address this challenge, all stakeholders, including the PwD themselves, should be involved in the design, development, and evaluation processes. When developing guidelines for design with PwD, Hendriks et al. (2013) found it almost impossible to formulate guidelines that could cover every PwD since dementia follows a specific course with each individual. More studies are needed to establish even the most basic requirements arising from dementia (Hendriks et al., 2013). Lindsay et al. suggest undertaking design-related activities with PwD in small groups and adopting a familiar and easygoing attitude. Participants are more likely to feel comfortable and discuss matters among themselves if a solid basis of trust is created (Lindsay et al., 2012).

In the case of PwD and their caregivers, using a participatory design method can facilitate appropriation by allowing a deeper understanding of their unique symptoms, difficulties, and needs; the collective development of design decisions; and the early integration of all stakeholders in the design and evaluation processes (Slegers et al., 2013). Furthermore, by broadening the scope of our approach, we are also addressing Mayer and Zach's complaint that traditional participatory methods are insufficient when managing PwD and that user studies often generate only limited insights (Mayer & Zach, 2013a). While effective participatory design–based research is feasible with PwD, it is not without its challenges (Hendriks et al., 2014; Hubbard et al., 2003; Louise, 2009). As caregivers are often overstretched, gaining access to them and the individuals they are caring for can be difficult. Beyond recruitment, interviews can be challenging as PwD may not have the capacity to provide sufficient feedback.

People with dementia can be limited in their verbal communication, memories, decision-making ability, and emotional stability. Successfully involving PwD in a research process can therefore necessitate considerable effort being devoted to building trust and encouraging engagement. Karlsson et al. have thus suggested that familial or professional support to reconcile the issues that arise with ICT systems is a critical part of the integration of such technology among PwD. Caregivers may therefore have a vital role in the research and interview processes (E. Karlsson et al., 2011). In addition, it is not only a matter of identifying the needs of PwD but also one of considering and respecting the needs and interests of PwD and their caregivers and involving them all in the research activity. In 2016, Wan et al. presented a user-centered development process for a GPS monitoring system to be used to support dementia care for individuals with wandering behavior while assessing the practical and ideological issues surrounding care from a socio-technical perspective (Wan et al., 2016). Based on the "assumption that all the activities of organizational actors. . .in a cooperative project might contribute to the formulation of design goals," they sought to examine how understanding the practices of potential users can be viewed as contributions to design and how the practices of research participants can mediate possible contributions to the best practice. In a study by Foley et al. (2019), interactions with residents with dementia in a care setting were also considered "opportunities for collaboration." Their work revealed that by using tangible objects, "moments of (mutual) recognition and meaning co-creation were supported through anchoring collaborative actions and sense-making in the physical world." Participation in a conversation can also create a sense of belonging, with PwD being recognized for their basic needs and social contributions (Foley et al., 2019).

While several promising results of supportive technology in dementia care have recently emerged, the long-term interaction and sustainable use of these technologies and insights in stakeholder-oriented appropriation processes remain limited. Researchers and developers face different challenges in designing, developing, and evaluating technology and actively involving PwD (Suijkerbuijk et al., 2019). Studies that report on the methodology and evaluation of the experiences of integrating PwD themselves are lacking; further studies on their active involvement and co-designing in the context of dementia care are therefore needed (Suijkerbuijk et al., 2019). In the context of design for and with PwD, technological artifacts such as ICT-based training systems may have a different impact on the lives of PwD and their social environments than what was originally intended. The individual appropriation and social integration of technical artifacts into the daily lives of older adults with dementia thus seem to be crucial for appropriation and integration into routine practices and sustainable use. A key issue here and a motivation of this thesis is the lack of multiuser empirical studies that explore how ICT can support PwD and their relations within their social care networks and complex challenges of everyday life.

RESEARCH QUESTIONS AND CONTRIBUTION

Studies have confirmed that the progression of dementia and managing everyday life despite its consequences can be positively affected by several interventions and reduced through physical and cognitive activity (Eggermont, L., Scherder, E., 2006; Eggermont et al., 2006; Ruan et al., 2015). Exercise and training can increase physical abilities, cognitive resources, the scope of social interaction, and psychosocial health (Gajewski & Falkenstein, 2016; Peluso & Andrade, 2005). Blankevoort et al. (2010a) found that physical activity with multifaceted interventions that involve endurance, strength, and balance exercises is beneficial at all stages of dementia as it results in notably greater improvements in walking speed, functional mobility, and balance than exercises involving only strength training.

Several studies have also illustrated that physical training can improve the mental health (Patricia Heyn et al., 2004), cognitive performance (Colcombe & Kramer, 2003), and physical resources (Hauer et al., 2012) of PwD, enhancing their capacity to cope with the challenges of everyday life (Kemoun et al., 2010). In addition, creative activities, such as art therapy and music-based activities, can benefit sociability, increase self-esteem, and create meaningfully positive stimulation for PwD (Hannemann, 2006; Logsdon et al., 2007; Sarkamo et al., 2014). Music in particular has come to the fore as a resource for interacting with PwD since especially biographically relevant music can facilitate individual and social well-being, as well as awaken memories, even in an advanced stage of dementia, based on its emotional significance. Different studies have reported that music-based activities can support the treatment of dementia-based symptoms, including fear and anxiety, positively influencing individual moods and behavior (Fang et al., 2017; Wall & Duffy, 2010). Regained language skills, increased well-being, reduced negative emotions, and increased self-esteem have all been observed during music-based activities with PwD (Grümme, 1998). Altogether, art and music activities can contribute significantly to the well-being of PwD, alleviate challenging situations, and improve the quality of life for both PwD and their social care networks.

In this context, studies have indicated that interactive assistive technology systems may stimulate and support the pursuit of physical fitness at home among older adults, enhance PwD's interpersonal relationships, and promote social well-being (Mélodie Boulay et al., 2011; Férnandez-Calvo B., Rodriguez-Pérez R., Contador I., Rubio-Santorum A., Ramos F., 2011; Weybright E., Dattilo J., Rusch F., 2010; Yamaguchi et al., 2011a). Most dementia-related technology focuses on the safety, physical and cognitive stimulation, and entertainment of PwD (Lorenz et al., 2019). In this regard, video games, particularly exergames, have recently demonstrated considerable promise. Studies have revealed that video games can lead to improvements in fitness, adherence, and balance, regardless of age (Anderson-Hanley et al., 2012; Colombo et al., 2012; Garcia et al., 2012; Göbel et al., 2010a; Ogonowski et al., 2016b; Vaziri et al., 2016a). Moreover, combining physical, cognitive, and socio-emotional activities, exergames could further support PwD by promoting social interaction and collaborative activity, thus alleviating symptoms of dementia.

However, few empirical studies examine the potential to support PwD and their caregivers in managing the challenges of social and daily life in their real-world environments. A pressing need for more focused studies in HCI that consider aspects of person-centered care and can therefore inform the ongoing development of ICT-based systems, such as exergames, with practical impressions, experiences, and emotions from PwD and their social care networks has thus arisen. Little research investigates the potential of exergames to promote physical activity, social interaction, and collaboration between PwD and other individuals, such as relatives and informal and professional caregivers, in their social environments. An inspection of the literature reveals a research gap regarding the assessment of the long-term effects of exergames on PwD in the context of their social environments and the role of relatives and professional caregivers in regularly mediating and integrating technology into the daily lives of PwD.

This thesis therefore focuses on the evaluation of the exergame-based system that was designed for PwD and their caregivers. During that process, PwD and their relatives and caregivers were involved as co-designers to provide their thoughts about the system. This thesis provides some answers to these questions by examining the impact of the system on the social environment of dementia and the role of relatives and professional caregivers in supporting the lives of PwD. In the following paragraphs, we investigate the user experience, focusing on the joy of use and emotional interactions, and determine how the exergames affect PwD and their caregivers individually and socially. Our results could help designers better understand where to focus their efforts when designing technology for specific target groups. In the summarized findings, we provide various significant insights that became manifest through our analysis of the results across the different publications. This work therefore seeks to address the following three main research questions:

(A) How does the exergame-based system affect PwD and their social care networks, and how can such a system create opportunities to improve health, quality of life, and well-being in the context of dementia care? Specifically, we consider the impacts on the physical and cognitive capabilities of PwD while they are using the system and after they have used the system over a longer period of time.

(B) To what extent can the exergame-based system initiate social interaction, foster social activity, stimulate meaningful interactions, relieve the challenges of daily care, and enable social impacts for social care networks? What processes do caregivers recognize as an important part of the social appropriation of technology, and how can the exergame-based system enrich and support the complex routines and challenges that the relatives and professional caregivers of PwD face every day?

(C) How should exergame-based activities be designed to positively affect individual capabilities and consider the social environment of dementia? To help designers and researchers in the fields of HCI and CSCW better understand where to focus their efforts when designing ICT or exergames for PwD, we investigate general and specific factors involved in designing video games that could encourage their long-term use and sustainability. This work therefore contributes to filling this research gap and expanding the current discourse on HCI and dementia by examining the impact of a suite of exergames that were designed to support the daily life activities of PwD and their social environments.

METHODS AND RESEARCH DESIGN

The Research Project: MobiAssist

This work is part of the three-year interdisciplinary research project called MobiAssist, which involves different research partners from diverse domains, including sports and nursing sciences, care software engineering, and game development, as well as institutions concerned with the care of older adults. A basic model that had been developed for a previous project (2011–2014) and aimed at assisting older adults at risk of falling was available at the beginning of this research project in November 2015 (Gschwind et al., 2015; Ogonowski et al., 2016a; Vaziri et al., 2017b). This model, which had been refined throughout the previous project, was adapted to the new target group, allowing for the ongoing observations, evaluation, and user feedback. Some prior game and training concepts, especially the strength games and reaction assessments, were preserved and converted into a new game engine (Unity), modified for the new target group, and simplified, while other games were excluded from the system for requiring an excessive level of physical and cognitive skills. The objectives and vision of this project concerned improving the physical and cognitive activity of PwD and offering sources of relief to their social care networks.

Study Design and Research Stages

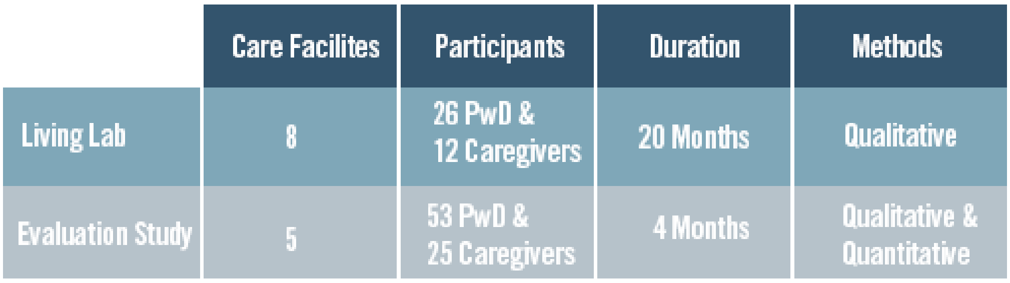
The study design was structured as (1) a two-year LivingLab to regularly evaluate and redesign the prototype together with PwD and their caregivers and (2) an eight-month multi-centered evaluation to assess how the system was used without any regular support from the researchers. Within this LivingLab, a research infrastructure for long-term user involvement in a participatory design approach and evaluation procedures was established (Eriksson et al., 2006). Qualitative preliminary studies were therefore conducted within the scope of identifying relevant usage contexts, determining requirements, and repeatedly redesigning early models while considering the feedback of PwD and their social care networks.

In the LivingLab studies (see Table 1), which lasted from January 2016 to November 2017, we explored the existing practices, organizational and social perspectives, and individual and social needs and challenges that PwD face in their everyday social surroundings. This process involved semi-structured interviews and observations of daily activities in different day-care centers, care facilities, and households to gain meaningful insights into the daily lives of

PwD. We also conducted interviews with informal and professional caregivers, as well as other stakeholders from related disciplines, including practitioners, therapists, and experts from the Alzheimer's Society. From the outset, the LivingLab approach thus enabled open collaboration among various actors, reflecting their different knowledge, interests, and expectations. In close cooperation with partners who provide care services, we recruited six care facilities and three ambulatory care institutions to present the overall project and establish long-term partnerships as soon as the project began. Additionally, we visited regional dementia networks, political actors, NGOs, physiotherapists, physicians, therapists, and self-help groups for PwD and their relatives to present the project and extend the partnership network. In several iterative steps, exergames were designed and deployed in many care facilities, where more than 20 PwD and their 12 caregivers regularly interacted with the system in different stages. For the iterative deployment, the exergame-based system was modified according to the observations of the PwD and their caregivers and the interviews that had been conducted during previous research stages. Throughout this stage, the participants' interaction and experiences with the exergames were regularly assessed across the different settings, with the system constantly being redesigned, refined, and extended to reflect the insights that arose from our observations of its use and the feedback we received from the PwD and their formal and informal caregivers. We proceeded in this manner to examine the potential of this system for all the relevant stakeholders. In keeping with a participatory design approach, we were particularly keen to involve PwD and their caregivers as co-developers, drawing upon their different knowledge, interests, and aspirations as the research and system evolved. There followed a short period of redesign where the insights that arose from the LivingLab study were assimilated to develop a more complete model for the multicentered evaluation study.

In the multicentered evaluation study (see Table 1), we deployed the system in a different set of households, daycare centers, and care facilities. The purpose of this study was to attain a concrete understanding of how appropriately tailored technical solutions for the target group (PwD and their caregivers) will need to be designed as other similar systems are developed in the future. The main evaluation study followed the research design of a multicentered intervention study, with a project start date of November 2017 and a project end date of October 2018. Over four months, the study examined the interaction of 53 PwD and 25 of their caregivers with our system. This examination occurred across different settings, including daycare centers, care facilities, and domestic households. The caregivers were asked to set up and use the system according to a daily training plan that was based on sports science–related evidence.

We wrote and distributed a manual on how to use the system and its games and introduced it to the participants in two general onboarding meetings at their institutions or homes after the initial deployment. The purpose of this approach was to examine how PwD and their social networks would use the system.



	Care Facilites	Participants	Duration	Methods
Living Lab	8	26 PwD & 12 Caregivers	20 Months	Qualitative
Evaluation Study	5	53 PwD & 25 Caregivers	4 Months	Qualitative & Quantitative

Table 1: Overview of LivingLab and Multi-centered evaluations study

Participants and Settings

The contacting and recruiting of PwD and their households proved to be difficult. In the first interviews with PwD and their relatives, we discovered that their social environments are so constrained by time and emotions that contacting them without a mediator is all but impossible. We therefore contacted more daycare centers. In an early research stage, we worked together with three ambulatory care institutions and six daycare centers around the city of Siegen. To obtain a comprehensive picture and diverse impressions, we deployed the exergame-based system in different households and daycare centers over 20 months and collaborated closely with the care institutions and participants to regularly evaluate and redesign the exergames. We visited the different care institutions individually twice a week to conduct moderated training sessions. We also visited participants at their homes regularly, usually once or twice a week. In both settings, we provided regular weekly supervision and moderation to help if technical problems occurred. Furthermore, we supported, motivated, or simply played the exergames with the participants to observe and understand their reactions. The system was permanently installed in the daycare settings. Most care institutions participated for four to six months; however, one daycare center and one care facility were involved for the entire project period and even after the project had ended. Two researchers visited the day-care center twice a week to moderate the sessions and help if needed. The researchers applied a division of labor, with one moderating the session and the other taking notes, so that one of them was always available to help the PwD without distraction. The system was installed in specific rooms in the facilities. Fixed installations also occurred in households. Here, in contrast to the daycare centers where the researchers conducted the sessions, the PwD and their relatives were asked to familiarize themselves with the game and train regularly.

The LivingLab studies (see Chapters 5–7) covered the exploratory empirical research and work for the first two years of the project, which concerned 26 PwD in households and eight care facilities (care homes and daycare centers). The number of participants in a session varied since all participants were not in the care facility every day. The sessions in the daycare centers permanently included three to six regular participants with diagnosed early- to mid-stage dementia, aged between 70 and 90 years. It also depended on the health and mood of the participants, who did not always want to play. Outside the sessions, the training room was left open so that every guest in the facility could go in and play. Informal and professional caregivers, as well as physiotherapists, also participated in the moderated sessions to some degree. Participants in private households needed to have a TV with an HDMI port at their homes, with at least three meters of space in front of it, so that they could use the system without risking injury. No financial compensation was offered to the participants. For health and personal reasons, the number of participants declined over time.

The main multicentered evaluation study (see Chapter 8) included 53 adults with early- to mid-stage dementia and 25 informal and professional caregivers in three different cities. Of these participants, 23 attended care facilities, and most attended various sessions regularly. The inclusion criteria for the study were a diagnosed early stage of dementia, the informal consent of the PwD's physician, and the consent of the PwD. Participants were excluded from the study if (1) their dementia was beyond a moderate stage; (2) they had in-parallel chronic diseases such as cardiovascular illness and cancer; or (3) their physical fitness was impaired such that they could not walk without assistance. Relatives were asked to self-report on the general conditions, capabilities, and diseases of the participants; professional caregivers then confirmed this data. It is worth mentioning that the different settings were subject to specific empirical investigation. One of these was the ambulatory care setting, where the system was deployed and executed at individuals' homes; the other was the stationary care facilities and daycare centers, where the PwD are guests for the day but return home in the afternoon. No financial compensation was offered to the participants.

Data Collection

The presented studies were formulated as design case studies as Wulf et al. (2011) originally articulated. This methodology consists of three ideal stages: (1) a pre-study that involves the empirical analysis of existing individual and social practices in a specific field; (2) the design of innovative ICT-based artifacts related to the findings from the pre-study; and (3) an investigation into the interaction with and appropriation of the designed technical artifact over an extended period.

To establish close cooperation between researchers, care providers, and end users, we established a LivingLab network at the beginning of the project and applied participatory research methods throughout the project. Nontechnical research questions, especially ethical, legal, and social issues (ELSI), were also considered, as the development and evaluation in the later usage context occurred in different settings and with various actors and their practices in their real-world environments. Stakeholders and participants were invited to be co-designers during the design, development, and evaluation processes. In terms of data collection, we deployed the system in the different stages of the project in assorted sets of households and care facilities. The long-term establishment of the LivingLab approach and its continuous visits over the project period, which included visiting participants at their homes and facilities once or twice a week to conduct training sessions, enabled and fostered close collaboration with the PwD and care institutions. In both settings, we provided regular weekly supervision and moderation to help if technical problems occurred; we also supported, motivated, or simply played the exergames with the participants to observe and understand their reactions. In the daycare settings, the system was permanently installed in the group activity rooms. Two researchers visited twice a week and moderated group sessions with around four to eight permanent participants. The researchers applied a division of labor, with one moderating the session and the other taking notes, so that one of them was always available to help the PwD without distraction. The system was installed in specific rooms in the facilities, where the training occurred. Fixed installations also occurred in households. Here, in contrast to the daycare centers, the PwD and their relatives were asked to familiarize themselves with the game and train regularly. In most households, the PwD and their relatives had no problem operating the system themselves and developed their own training schedules.

Semi-structured interviews and observations were conducted in households and care facilities. In an early stage of the project, the interview questions focused on the biographies of

PwD, their daily routines and physical and cognitive resources, and the effects of dementia on their individual and social lives. Participants were encouraged to elaborate freely on these topics. All interviews were conducted face-to-face, audio recorded, and transcribed. The interviews lasted 30 to 120 minutes each and were supplemented by observations of participants' interactions with the system. All the data were enhanced with research notes that captured individual experiences and observations across the household and daycare settings, including our regular exchanges with the participants via e-mail and telephone.

In addition, several sets of design workshops with different foci were conducted in care facilities. These workshops were structured as follows: introduction, focus group interview, mapping, ideation, and discussion. In the introduction, we became familiar with the participants and their ways of working, the care structures, the activities and interventions that daycare staff offer, their experiences with technology, and their expectations. After the first set of workshops, we analyzed the outcomes and their implications for the next round of design. In the second set of workshops, we created paper-based models and design mockups that attempted to address the stakeholders' needs and expectations uncovered during the first set of workshops. Based on the results, we then explained what elements would be needed to develop the game, which led to a focus on specific aspects, such as the graphical arrangement of objects, different game mechanics, levels, required speed and movements, degrees of difficulty, and user interface. In the third set of workshops, the nature of the virtual environment and general functionality became the focus.

Multicentered Evaluation Study

Over four months, we conducted a multicentered study that examined the interaction of 53 PwD and 25 of their caregivers with our system. In the study, informal and professional caregivers functioned as technology mediators. This study thus focused on these caregivers' (social) appropriation and perception of the system, motivated mainly by the following research questions: What processes do caregivers recognize as having an important role in the social appropriation of technology, and how exactly are systems socially appropriated and contextualized in everyday life? The evaluation study occurred across different settings, including daycare centers, care facilities, and households, and involved PwD and their informal and professional caregivers. The caregivers were asked to set up and use the system according to a daily training plan that was based on sports science–related evidence. We created individual training plans and recommended at least 15–20 minutes of training a day with and in front of the system. Participants were advised to begin with the training plan, and then, if they wished, they could continue in free game mode. We wrote and distributed a manual on how to use the system and games and introduced it to the participants in two general onboarding meetings at their institutions or homes after the initial deployment. The purpose of this approach was to examine how PwD and their social networks would use the system without the regular support of the researchers. Assessments and interviews were performed with participants and their relatives and professional caregivers. During the initial assessment, sociodemographic, health, and care-relevant information was acquired, and semi-structured interviews were conducted. Physical and cognitive tests were also executed before and after the system evaluation. Here, we focus only on the qualitative data. Overall, 69 interviews were conducted with PwD and their caregivers before and after the multicentered evaluation study.

Data Analyses

The qualitative data consisted of audio recordings and field notes collected during the interviews and observations throughout the project. After the full transcription of the interviews was completed, the transcripts were reviewed and coded. Data analysis was performed by using thematic analysis (Braun & Clarke, 2006a), following a series of established steps, including the coding of the material, systematic revision of the coded segments, and identification of code families and their relationships, in the search for themes (Braun & Clarke, 2006a; Gibson et al., 2015). As result categories derived from our semi-structured interview guidelines and original codes—which included aspects such as motivation, facilitating memories, audience participation, engagement, and movement—were created, coding differences were discussed and eliminated by adding, editing, or deleting codes. Several empirical codes that were used to encode relevant data excerpts across the entire collection of empirical data were identified. Moreover, the relationship between codes to identify and develop our themes (Braun & Clarke, 2006a) was investigated further. All the interviews and field notes were anonymized, encrypted, and stored on a university platform that is not used for commercial purposes. To triangulate our data, we adopted three strategies: (1) discussing the same topics with relevant actors at different times and in varying levels of detail, (2) discussing similar topics with different actors, and (3) discussing our findings within the project team, which included experts from the fields of sports and nursing sciences, as well as experts from NGOs.

Ethical, Legal, and Social Considerations

Based on the ethical boards' recommendations to ensure participant privacy and data security, the interviews with PwD and their relatives were conducted in consideration of different documents to respect and ensure the privacy of personal data. These documents were prepared according to legal provisions and valid only when combined with a personal declaration of consent, which the participants could revoke at any time. Additionally, to avoid medical complications, a medical declaration of no objection, in which each participant excludes certain medical risks, was prepared. The mentioned documents were part of the University of Siegen's first ethics approval, which occurred in 2016. The guidelines for data processing for scientific purposes were therefore considered, and the participants were informed that within the framework of the research project, data collected from the interviews, particularly information about their health, would be recorded in paper and electronic format at the University of Siegen. The personal data covered participants' names, ages, genders, occupations, and information regarding their states of health, as well as their emotional states. The evaluation of the data was performed anonymously, and no personal data were disclosed. Another component was our commitment that in the event of the revocation of a participant's consent, all personal data would be deleted immediately and completely and not processed further. The University of Siegen's ethical committee approved the final evaluation study in 2017; this approval was related to patient recruitment for the main study. Based on the experience we gained during the LivingLab studies and the pilot study in spring 2017, we prepared the ethical documents, considering not only ethical and data protection aspects but also medical findings.

System Overview

A basic prototype was already available at the start of the overall research project (in Nov 2015) that had been developed for a previous project (iStoppFalls, 2011-2014), aimed at improving and assisting older adults in general with a risk of falling (Gschwind et al., 2015; Ogonowski et al., 2016a; Vaziri et al., 2017b). The technical infrastructure and the games were still applicable because the majority of the games focused on strength and balance, which are important factors for fall prevention. This prototype had been refined and adapted to the daily life of PwD, drawing upon the ongoing observations, evaluation and user feedback. Some prior exergames and training concepts (especially the strength games and reaction assessments) were transfered and converted into a new game engine (Unity), changed for the new target group and simplified, while other games were no longer included in the system because they required too high a level of physical and cognitive skill.

The final interactive system can detect all movements (upper and lower limps, head and body movement) and training activities of the participant using the Microsoft Kinect Sensor. The system consists of several technical components (see Figure 3). The technology was centered around a TV (4) to provide an easy and familiar way through which it can be accessed. The system runs on a mini-computer (1) that includes several exergames (2) and is connected with a MS Kinect (3) to detect the movements of the participant when interacting with the system. A male and female 3-D model and an underlying biomechanical model were provided for the Kinect-based motion detection (see Figure 3). Furthermore, a level structure (7) for each Exergame with over 30 Levels per game are provided. After playing the basic levels, the difficulty degree increases, and more and more dual and cognitive tasks appear. The participants are encouraged to play the “daily training schedule” to proceed in the system and reach higher levels. The daily training schedule covered a range of 4-5 exergames, consisting of movement, coordination and creativity games. Outside of the daily training plan, players are able to choose and play the games on their own in the “free game mode”. The system is connected to a cloud system (8) that is used as a backend information platform to create users, initiate training schedules and to detect level progression.

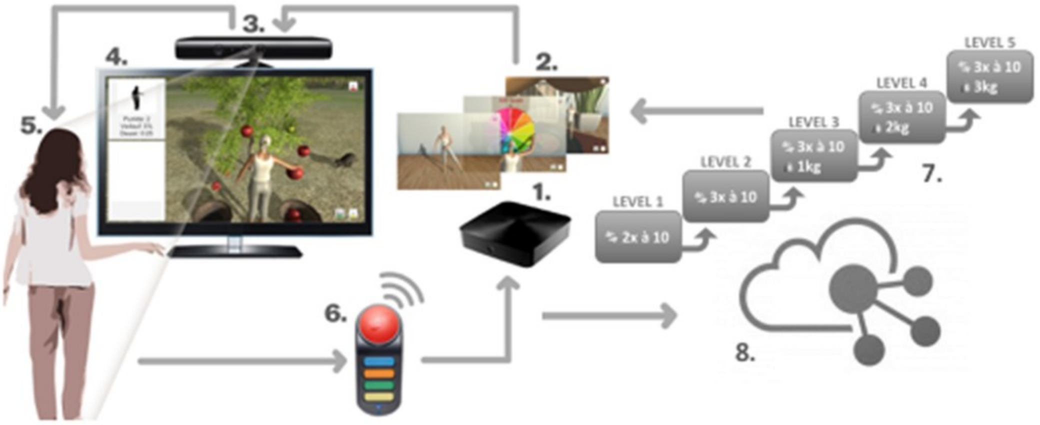


Figure 2: System overview

To simplify the interaction with the overall system, a PlayStation 3 Buzzer (6) was used as a navigation tool and input device during the games (e.g. to choose an answer during a quiz). The system has three different exergames core elements: 1) Movement games and Assessments, 2) Coordination and Balance Games, and 3) Cognitive and creative activities.

Training schedule and progression

Exercises and games, as well as tests to measure performance and reaction ability, were developed and selected from the fields of sport science, sport gerontology and nursing science. The aim was to train the physical activity and to measure the level of activity over a longer period of time.

Trainingsplan

Heute ist der 26. Juni 2018. Hier sehen Sie Ihren Trainingsplan für den heutigen Tag:

Spiel 1:	Knie strecken
Spiel 2:	Knie beugen
Spiel 3:	Frische Früchtchen
Spiel 4:	Rate Runde
Spiel 5:	Musik Marathon

Heute enthält der Trainingsplan keine Fingerspiele!

Figure 3: Training plan

The program focused on virtual exercises that are necessary for the execution of everyday activities (e.g. climbing stairs, carrying bags, and sitting to standing transfers). The level structure is controlled by an individual training schedule. After the player reaches the minimum points of a level, the level increases, but each level can also be maintained, ascended or reset without receiving a de-motivational notices.

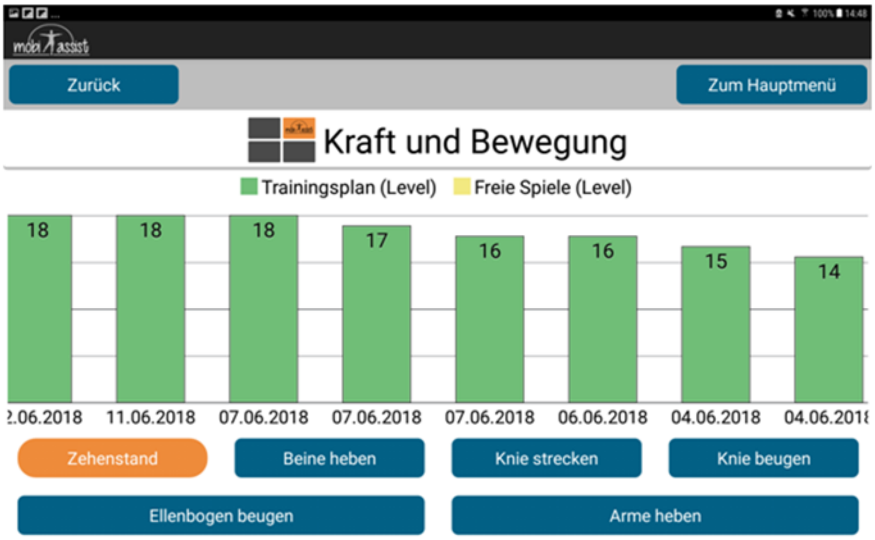


Figure 4: Training plan tracking

Strength Training and Assessments

The strength training includes exercises for the upper and lower limbs such as: knee extensors to strengthen the front thigh muscles; knee bends to strengthen the rear thigh muscles; sideways leg raises for the lateral thigh muscles; toe-stands for the calf muscles; elbow bends for the upper arm muscles: and front raises for the shoulder muscles.

Figure 5: Strength exercises and assessment

The strength exercises focus on lower and upper limb muscles, which are important during functional movements like walking or balance. To ensure safety, the program recommends holding on to at least one chair for support. However, for people with dementia all exercises begin at the lowest intensity to enable the user to familiarize themselves with the technology, the real-time feedback and the quality of their movements. Each exercise gradually increases in difficulty as the program progresses with the training progress in order to maintain at least a moderate intensity. The strength exercises are progressed through increasing the level of physical activity, the difficulty of cognitive dual tasks and increasing number of repetitions.

In addition, the assessment integrated in the strength program measures physical performance with tests for balance, lower limb strength, hand, and stepping reaction times It includes semi tandem, near-tandem, and full-tandem balance tests, where the participants were asked to hold the stance for 30 seconds without moving their feet. The hand and stepping reaction time test showed how fast the participants can react, if a signal lights up. The strength test included the sit-to-stand activity: Here, participants had to stand up and sit down five times in a row and the system measured the time, which it took to fulfill the task. Based on the speed. It was possible to compute the strength.

Balance and coordination

The focus of the balance and coordination games is to solve percipience, balance, reaction and aiming tasks in a playful fashion. Therefore different games were developed with the project partners and the participants as well as there caregivers.

Walking game: This game requires from the player to lift the knees to a specified height (running in place) to move forward. In higher levels, more and more dual tasks are appearing, for example bumblebees are flying towards the players, who have to be avoided by shifting the body sideways. In addition, flowers and cacti appear at the wayside, which must be collected or in the case of a cactus avoided as well. For this, the player stretches out his respective arm as he walks past the flowers. Furthermore, in an advanced stage of the game, a deer cross the path. Players have to wait until the animal successfully crossed the street, otherwise the player will not collect special points. This exergame is mainly about the strengthening or maintenance of condition, flexibility and to promote coordination. In terms of agility, the focus is on walking ability on short distances and on longer distances, it is about maintaining concentration to walk in a limited field and to complete the dual tasks.

Figure 6: Games Overview

Apple game: This game aims to increase or maintain the radius of movement of the upper extremities. The goal-oriented stretching and grasping of virtual apples is to maintain the users' resources to face everyday tasks (preparing food, grabbing something above their head or washing the upper body or head) The apple in the treetop is reached by the player with his arms or his hands. A ripe apple must be picked and collected in a basket, which is placed next to the player. Special apples are visually recognizable (golden shimmer / flashing). The player stretches his arm in his direction and logs the apple, in which he lingers with his hand for a short time over the apple, then he leads the apple in his hand towards the basket. When lowering the arm with the apple below a predetermined threshold value, the logged-in apple falls from the hand into said basket. If an apple is missed, it becomes rotten or falls to the ground where it is collected by cheeky animals that relish the fruits. Pickled apples leave a blossom that grows into a new fruit. A level is defined by the number of fruits collected within a certain time limit. The speed (even for failed levels) is tracked in the background. Missed apples are listed in the results screen. This exergame is mainly about strengthening and coordinating the upper extremities, in higher levels coupled with smaller additional coordinative tasks.

Hit the moles: In this game the player stands in a virtual garden and in the front of the player, single moles emerge from mounds, one after the other, intending to destroy the garden. By stepping with one foot on the appearing mole, the animal is expelled, and the garden saved. After that, players must return to their starting position until the next “troublemaker” appears. As a dual task, a player should not step on possibly other emerging pets like birds. The movements are designed to promote the coordination of the lower extremities, to support the condition and balance during ongoing training and to improve reaction time and therefore, prevent possible falls. This game should lead to a safer walking and standing of the users as well as a greater motor self-confidence.

Airplane Game: The game is about mobilizing and maintaining upper body flexibility. In higher levels the movements are coupled with small additional cognitive tasks to promote coordination and strengthen cognitive attention. The player steers a small plane through a air-parkour. By leaning to the side of the upper body, the player controls the plane through gates on the water and in the air. Sometimes Zeppelins block the direct path through the gates and should be dodged. Reversing or leaving the track is not possible to achieve reasonably comparable results. The game starts automatically via the training schedule or is selected via the menu. Here, only levels can be played, which were already successfully completed during the training. A level is defined by the completed route and the associated time limit, the flight speed and the number of gates and Zeppelin.

Creativity and Cognition

The creativity and cognition aspect were developed together with professional caregivers and therapists who work with people with dementia on a daily basis. These exergames cover a variety of games that combine movement, creativity and cognitive tasks.

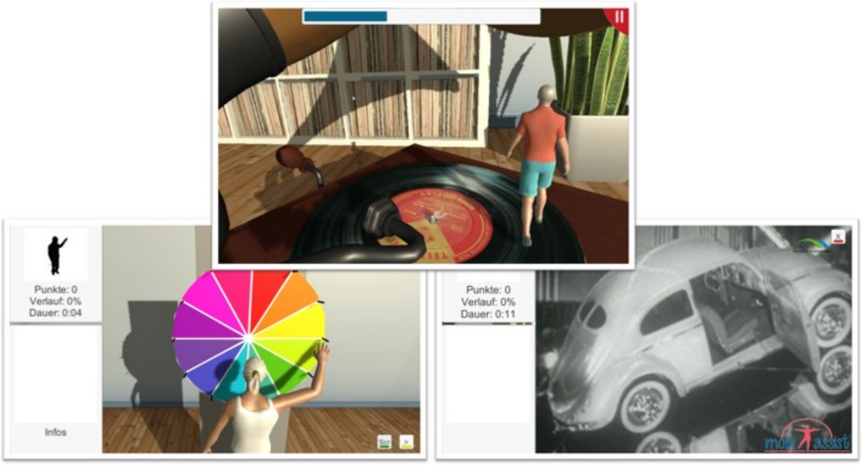


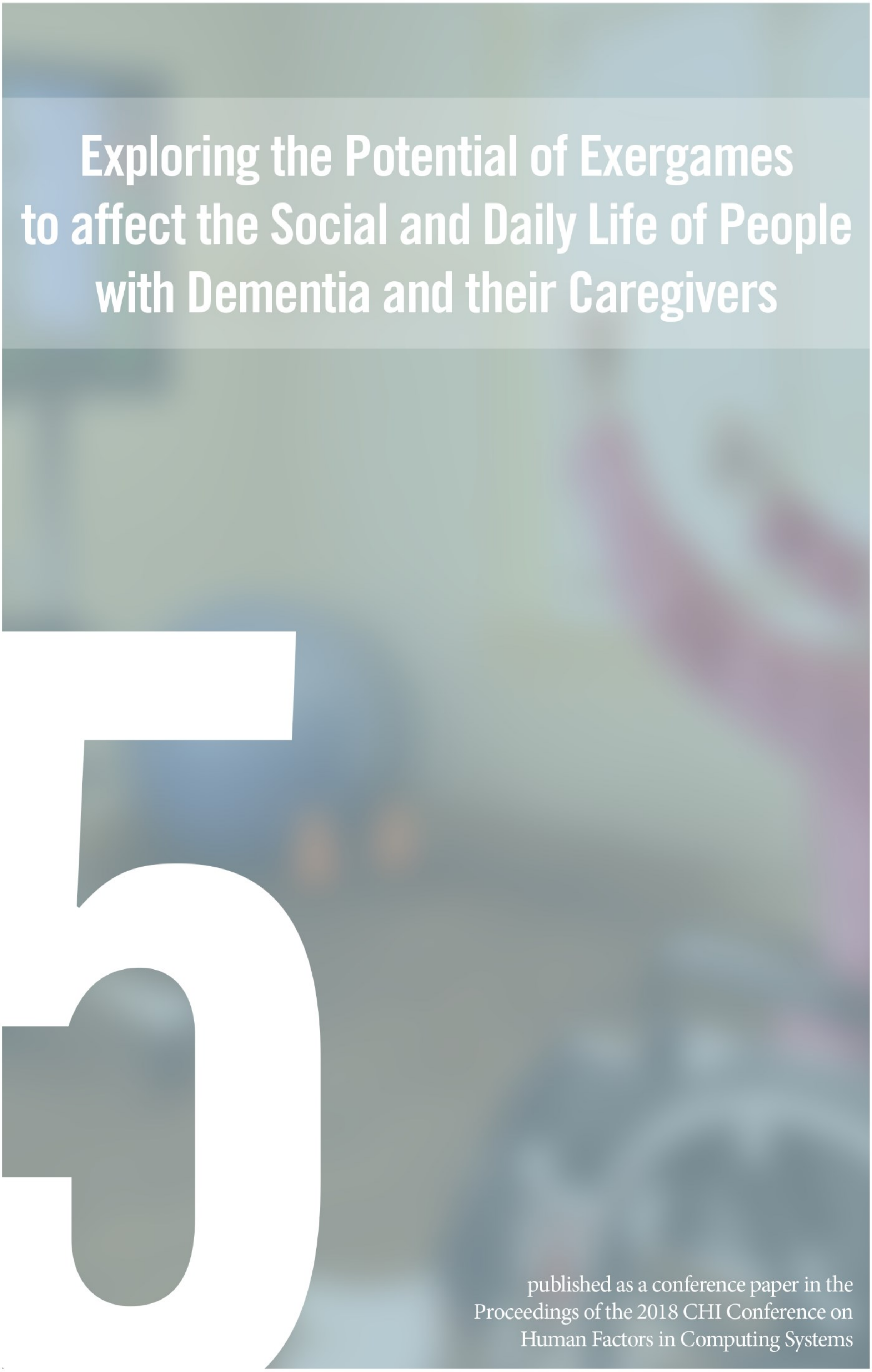
Figure 7: Overview Creative and Cognitive Games

Movie Theatre: This exergame is mainly about the memory manifestation and initiating discussions about the presented content. The movies are automatically retrieved and visualized by the system and can therefore be understood as a communicational gateway to memories and starting point to biographical information, rather than a physical or cognitive task. This presentation of historical videos should contribute to the secondary manifestation of these memories and refresh them. The memories consist of historical as well as autobiographical material, which are stored in a database. Partner for this project was the company "History Vision GmbH from Berlin", whose library we can use cooperatively for this research purpose.

Wheel of fortune: This exergame is primarily about strengthening memory and knowledge through a quiz. Various topics are addressed, such as music, proverbs, everyday items, animals, objects, rhymes or math problems. The topics are selected via a wheel of fortune with colored fields that represent different categories. Players can interact and start the game by grabbing one of the outer pins with the hand and swinging the wheel into rotation. The wheel must - to ensure the randomness - at least make a complete turn before it stops on a topic. After that, the task automatically opens and is to be solved on a wall in four different answer fields. To do this, the players use the Buzzer to log in the correct answer. Depending on the category, this has different effects. In a math task, the player only sees if his result is correct. When completing proverbs or lyrics, the game should complement acoustic confirmations of the answer.

Quiz: This exergame is primarily about the strengthening of everyday life through a manifestation of everyday knowledge in quiz form. The, overall 225, everyday questions and answers serve to strengthen cognitive everyday life skills, such as the recognition and naming of everyday objects or the recognition and application of communicative and especially linguistic memories in an increasing difficulty. Players must be able to understand abstract categories in order to answer the questions and thus strengthen organized thinking.

Music Game: This exergame is primarily about strengthening and endurance of the lower extremities. The playful running exercises take place in a virtual setting on a spinning vinyl disc. The player acts as a needle on a vinyl player and can be played by his run previously selected pieces of music. After selecting a new title in the menu, the player functions as a needle of a turntable placed in the room and, by running, moves the turntable, causing the corresponding piece to sound. If he stops running or becomes too slow, the volume of the selected track will decrease or it will stop altogether. The pieces are previously stored in a database and both user-specific and general preselected pieces with the corresponding titles can be selected. The pieces are archived based on their length. A piece of music is thus defined by the music direction, but also by its length and can thus be sorted in levels.



Exploring the Potential of Exergames to affect the Social and Daily Life of People with Dementia and their Caregivers

5

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EXPLORING THE POTENTIAL OF EXERGAMES TO AFFECT THE SOCIAL AND DAILY LIFE OF PEOPLE WITH DEMENTIA AND THEIR CAREGIVERS

Abstract

This paper presents the outcomes of an exploratory field study that examined the social impact of an ICT-based suite of exergames for people with dementia and their caregivers. Qualitative data was collected over a period of 8 months, during which time we studied the daily life of 14 people with dementia and their informal and professional caregivers. We focus on the experiential aspects of the system and examine its social impact when integrated into the daily routines of both people with dementia themselves and their professional and family caregivers. Our findings indicate that relatives were able to regain leisure time, whilst people with dementia were able to recapture certain aspects of their social and daily activities that might otherwise have been lost to them. Results suggest that the system enhanced social-interaction, invigorated relationships, and improved the empowerment of people with dementia and their caregivers to face daily challenges

Introduction

Dementia is one of the most common mental illnesses in old age and affects almost every care recipient in ambulatory care (Bundesregierung, 2016). The issues confronting relatives, caregivers, health and care providers, and the health care system in general is huge. There are currently 1.6 million people with dementia in Germany. According to forecasts, this number will rise to 2 million by 2030 and to 3 million by 2050 (Deutsche Alzheimer Gesellschaft e.V., n.d.; Sütterlin, S., Hossmann, I., Klingholz R, 2011). Ongoing changes in the demographic constitution of societies, with the decline of the so-called nuclear family, increased work mobility, and shifting patterns of income and social security benefits, present a considerable challenge to the ways in which care may be provided to older adults and people with dementia (Rosen et al., 2011). With both early-stage and advanced dementia the ability to perform everyday social and other activities without any help from people such as informal or professional caregivers, is limited (Mioshi et al., 2009). Thus, dementia has consequences for both those who experience it and informal and professional caregivers who may well face increased stress on an emotional and social level. A further problem here is that dementia is likely to affect relationships between family caregivers, their relatives and the social structure of their family. Dementia, then, can be a disruptive force in a number of people's everyday lives.

However, research has shown that both the progression of dementia itself and managing everyday life around its consequences can be positively affected by a number of interventions. For example, the risk of developing dementia, and its progression, can be reduced through physical and cognitive activity (Eggermont, L., Scherder, E., 2006; Ruan, 2015). Exercise and training not only target an improvement in physical ability but also cognitive resources, the scope for social interaction, and psychosocial health (Gajewski and Falkenstein, 2016; Peluso and Andrade, 2005). In this context, studies have shown that interactive and assistive technology systems may stimulate and support the pursuit of physical fitness at home amongst older adults (Silveira et al., 2013) and enhance people with dementia's interpersonal relationships and promote social well-being (Mélodie Boulay et al., 2011; Férnandez-Calvo B., Rodriguez-Pérez R., Contador I., Rubio-Santorum A., Ramos F., 2011; Weybright E., Dattilo J., Rusch F., 2010; Yamaguchi et al., 2011a). Thus, there are ways in which the progression of dementia may be controlled, whilst supporting the autonomy of people with dementia and improving the quality of life for both them and their caregivers. There is, however, generally a lack of empirical studies that examine the potential to support people with dementia and their caregivers in coping with the challenges of social and daily life. Thus, there is a pressing need for more focused studies in HCI that can inform the ongoing development of ICT-based systems such as exergames.

In this paper, we report on results from an exploratory field study with an exergames prototype to support activities of daily living for people with dementia. The ICT-based system itself was designed and tested together with people with dementia and their caregivers. The system and the related exergames were developed and selected from the fields of sport science, sport gerontology and nursing science and it integrates for the first time different ideas (activity, cognition, creativity) based on established interventions from across those various disciplines. The underlying design objective here was the provision of a suite of activities that can give people with dementia support across their activities of daily living (ADLs), rather than single games with a unitary purpose. It is critical that this kind of over-arching design objective be accomplished in consultation with all of the possible stakeholders concerned. This cohesive vision and purpose is not present in the existing array of serious games available.

The specific goal of the study we are reporting here was to investigate if ICT-based exergames can affect the daily and social lives of people with dementia and their caregivers and support them in their individual and social needs, thus creating opportunities to overcome the challenge of how to integrate such systems in their daily routines. To this end, the authors initially conducted semi-structured interviews and observations in different day-care centers and households to get insights into the everyday life of people with dementia. Afterwards, the ICT-based exergames were designed and installed in different homes and day-care centers, which we then regularly visited over an 8-month period.

In the following sections we begin by providing an overview of the related literature in HCI and associated fields and an indication of how we are building upon this. We then explain how we approached the field study and tackled the analysis of the data it produced. This is followed by a brief outline of the system we deployed in people's homes and the day-care centres. We then present our findings regarding the impact of the system upon people with dementia and their caregivers, their social interactions, and the extent to which it was integrated in their everyday lives. Our subsequent discussion focuses in particular upon two research questions: (1) How do exergames affect the daily and social lives of people with dementia and their caregivers, and (2) What are the key factors that might facilitate integration of such technologies into their daily lives. We conclude by indicating how we will be building upon the study and developing the system in the future.

Related Work

The design of ICT-based systems for people with dementia and their caregivers requires designers to investigate and understand how dementia affects the social lives of the people involved and what interventions may counteract the progression of dementia. In this section, we examine previous work in the field of ICT for dementia, and look at the corresponding challenges that have been identified regarding the design of supportive ICT-based systems for people with dementia and their caregivers.

The challenge for informal and professional caregivers

Dementia has a particularly significant impact upon older adults, relatives and professional caregivers. The challenge of living with dementia and managing everyday life is of varying intensity according to the symptoms at different stages. This can have a more pronounced effect upon both professional caregivers and relatives providing care than other kinds of care for chronically ill patients (Koeppe et al., 2003). The relatives of people with dementia often have to cope with considerable physical, psychological, emotional, and financial burdens (Coon and Evans, 2009; Schulz and Sherwood, 2008)]. Having to organize and be responsible for care activities restricts family members and caregivers and results in a complete revision of daily routines and everyday life (Chassioti, 2014). Caring relatives are often also obliged to deal with complicated administrative matters such as: handling preventive measures and keeping their relatives occupied; negotiating with health and care insurers regarding the need for care for the person concerned; ensuring there is adequate care; completing documents; and applying for technical aids. The personal needs of caring relatives are often considered to be subservient to the needs of the people with dementia themselves, with carers being expected to re-organize their lives around them (Haas, 2012). As a result, relatives often reach the limits of their own physical and mental resilience. At the same time, private households may experience a loss of income because they can no longer maintain the same level of employment at the same time as managing the care needs of their relatives (Sörensen and Conwell, 2011). Without the possibility of relief, caring relatives are at increased risk of physical and cognitive diseases. This phenomenon has been characterized using the notion of "hidden patients". It is also sometimes referred to, in advanced cases, as "caregiver overload" (Bindel and Pantel, 2012; Takai et al., 2009). In our own work we extend upon this literature by examining how the deployed system was able to ameliorate certain aspects of caregiver overload.

Interventions to promote activities of people with dementia

Studies show that a healthy lifestyle and physical activity can help to reduce the risk of developing Alzheimer's or any other type of dementia. For example, DeFina et al. found that a high fitness level not only protects against the dangers of a stroke or diabetes mellitus, but can also provide protection from dementia in middle age (DeFina, 2013). Exercise programs are therefore promising because they not only mitigate the symptoms of dementia, but can also limit the associated risk factors. Other studies illustrate that physical training can improve mental health (P. Heyn et al., 2004); cognitive performance (e.g. information processing, coordination) (Colcombe and Kramer, 2003); and physical capacity (Hauer et al., 2012); thereby improving the everyday capabilities of people with dementia (Baker et al., 2010; P. Heyn et al., 2004). Numerous previous studies have established a positive correlation between the physiological aspects of mobility and activity and dementia (Eggermont et al., 2006; Katusic and Austin, 2014; Lahmann et al., 2014). Blankevoort et al., for instance, found that physical activity is beneficial at all stages of dementia. A multi-faceted intervention involving endurance, strength, and balance exercises resulted in greater improvements in walking speed, functional mobility, and balance than comparable exercise involving just strength training. Greater intensity and frequency of training can also lead to increased social participation (Blankevoort et al., 2010b).

In addition to physical interventions, creative activities, music and shared recollections may have positive effects on people with dementia. Art therapy, for instance, can produce benefits in sociability, improve self-esteem, and provide meaningful stimulation (Hannemann, 2006; Logsdon et al., 2007; McDermott et al., 2014; Sarkamo et al., 2014; Schmitt and Frölich, 2007). Music therapy both increases memory and enhances alertness and happiness. It has also been shown to reduce depression, improve people's outlook on life, increase their decision-making capability, and promote a sense of hope and thus improve their quality of life (Hannemann, 2006; Logsdon et al., 2007; McDermott et al., 2014; Sarkamo et al., 2014; Schmitt and Frölich, 2007). The design of the system deployed in our own study was actively inspired by a number of these previous kinds of intervention.

However, physical or non-physical training can also be burdensome on people with dementia and their caregivers. One common complaint was that it is hard for people with dementia to attend exercise classes because it places responsibility upon care-partners to get them there. ICT-based exergames, may therefore ease problems of access and reduce the logistical challenge placed upon caregivers and other relevant stakeholders. The potential of the kinds of ICT exergames we report on here, in that case, is that they could make an important contribution to the autonomy and quality of life of people with dementia and their caregivers, thus positively affecting their well-being (Dove and Astell, 2017).

Impacts of ICT in the field of dementia

In recent years a variety of projects have been launched in the field of ambient assisted living focused on improving the domestic care situation for people with dementia. Siriaraya and Ang (Siriaraya and Ang, 2014) investigated the effects of 3D-based virtual worlds on people with dementia in inpatient facilities over a period of eight months. They report that experiences and memories from virtual worlds can increase the self-esteem of older people with dementia. They also provide them with an escape from their constrained physical environment and transport them into a world of memories, potentially becoming a "holy sanctuary" where such memories can be sustained. In another, somewhat related project, a tablet-based memory game with biographical content was used as a source of stimulation for people with dementia. Here the results showed that even people with advanced dementia are able to use this kind of application without the support of nursing staff. Once again memory-based play was found to have a positive impact, this time with regard to emotional experience, behavioral problems, and interaction with other participants (Schultz et al., 2014).

Exergames - i.e. video games that involve physical exercise – have become increasingly visible in this arena. Studies here have suggested that exergames can result in general improvements in people's fitness, adherence and balance, irrespective of their age (Douglass-Bonner and Potts, 2013). Notably for our own case, exergames have been shown to have the potential to improve health and well-being in older adults (Gschwind et al., 2015; Vaziri et al., 2017a)(Ogonowski et al., 2016a). Further literature suggests that older adults are likely to accept exergame systems and use them on a regular basis (Ogonowski et al., 2016a; Vaziri et al., 2016b). In the context of dementia, *McCallum and Boletsis* (McCallum and Boletsis, 2013) *have suggested that exergames that aim to improve physical performance can positively influence several different factors amongst people with moderate Alzheimer dementia and mild cognitive impairment, including gait, balance, and motor control* (Legouverneur et al., 2011; Padala et al., 2012a). *Adapting to* new information and undertaking exercise can also lead to positive effects concerning learning and memory. *Thus exergames have also been found to enhance various cognitive capacities* (Rosen et al., 2011; Stavros et al., 2010; Weybright E., Dattilo J., Rusch F., 2010)*, and visual-spatial skills* (Yamaguchi et al., 2011a). Lack of social interaction can be a pivotal issue for older adults and people with dementia (Cattan et al., 2005). With respect to this, *exergames that combine physical and cognitive objectives may reequip people with dementia with capabilities and skills that facilitate social interaction and collaboration and thus help to ameliorate depression, anxiety, and stress* (Melodie Boulay et al., 2011; Férnandez-Calvo B., Rodriguez-Pérez R., Contador I., Rubio-Santorum A., Ramos F., 2011; Robert et al., 2014a; Weybright E., Dattilo J., Rusch F., 2010; Yamaguchi et al., 2011a)]. This, too, is something that is reflected in our own study and that we shall be returning to in the discussion.

Designing ICT for people with dementia

As designers, we need to be aware of the fact that technological artefacts, like ICT-based training systems, may affect different aspects in the lives of people with dementia and thus have the potential to "*become a technical infrastructure for a large diversity of different forms of social life"* (Pipek and Wulf, 2009). Here, integration of such artefacts into the daily lives of older adults with dementia seems to be key.

However, there is a discourse in the existing literature regarding barriers that can impede embedding technical solutions in the daily life of older people, and in particular people with dementia and their caregivers, because their daily routines are characterized by increased complexity (Gibson et al., 2015). This has resulted in a notable gap between technical visions and actual knowledge about the everyday lives of people with dementia and their caregivers in real-world environments (Fitzpatrick and Ellingsen, 2013). As pointed out in the introduction, a key issue here is the lack of multi-user empirical studies examining how people with dementia might be supported in coping with the challenges of everyday life. One of the principal ways in which our own work extends upon the existing literature is the provision of just such a study.

Current research in HCI suggests that the acceptability of a new technology and its scope for integration and sustainable use plays a significant role in how successfully it is adopted. Innovative technical design based upon participatory and experience-based research therefore offers a significant advantage with regard to uncovering and respecting the social, emotional, ethical and legal concerns and requirements of all stakeholders (Hwang et al., 2016; Lindsay et al., 2012a; Mayer and Zach, 2013a; Slegers et al., 2013; Wan, L., Müller, C., Wulf, V., Randall, D., 2014). In the case of people with dementia and their caregivers, using participatory design methods can facilitate appropriation by allowing the space for a deeper understanding of their own unique symptoms, problems and needs (Hendriks et al., 2014; Hwang et al., 2016; Wallace et al., 2013a), the collective development of design decisions (Dove and Astell, 2017; S. Lauriks et al., 2007; Mulvenna et al., 2010), and the inclusion of all stakeholders in the design process (Lindsay et al., 2012a). A further specific advantage of our own approach here is that participatory design-based research regarding dementia needs to move beyond single case studies (Hendriks et al., 2014). Additionally, by having broadened the scope of our approach, we are also addressing the complaint made by Mayer and Zach that traditional participatory methods are not sufficient when dealing with people with dementia and that user studies often only generate limited insights (Mayer and Zach, 2013a).

Whilst effective participatory design-based research is feasible with people with dementia, as our study demonstrates, it is not without its challenges (Hendriks et al., 2014; Lindsay et al., 2012a; Mayer and Zach, 2013a; Slegers et al., 2014). As caregivers are often already overstretched, getting access to them and the people they are looking after can be difficult. Beyond recruitment, interviews can be challenging because people with dementia may not have the capacity to provide sufficient feedback. People with dementia may be limited in their verbal communication, memories, capacity to make decisions, and emotional stability. Successfully involving people with dementia in a research process can therefore necessitate considerable effort being devoted to the building of trust and engagement. In view of this Karlsson et al (Eva Karlsson et al., 2011) have suggested that familiar or professional support to reconcile arising issues with ICT systems is a critical part of the integration of such technology amongst people with dementia. Caregivers may therefore have a vital role to play in the research and interview process (Brankaert, 2016a; Lindsay et al., 2012a; Mayer and Zach, 2013a; Slegers et al., 2014). Thus, it is clearly not just a matter of identifying the needs of people with dementia , but considering and respecting the needs and interests of both people with dementia and their caregivers and involving all of them in the research activity (Lindsay et al., 2012a).

The research gap

We have argued for a more holistic approach to the design of assistive systems above. Making such systems effective requires knowledge about how integration into the daily life activities of people with dementia and their caregivers might best be realized (Wulf et al., 2011, 2018). The literature suggests that exergames may deliver appropriate interventions that improve health in the areas of physical and cognitive condition and that such interventions, if used on a regular basis, may improve quality of life and well-being. We argue that, in order to integrate exergames in the daily lives of people with dementia and their caregivers and to create opportunities to improve health, quality of life and well-being in this target group, it is first necessary to understand how such systems affect their daily and social lives. Such knowledge may enable designers to derive relevant design implications that facilitate their appropriation, but it is not currently well-documented in the literature. The exploratory study presented here therefore contributes to filling this gap and expanding the current discourse in HCI and Dementia, by examining the impact of a suite of exergames that were expressly designed to support the daily life activities of people with dementia and their caregivers.

Methods

Our study draws upon research in both day-care facilities and domestic environments. It was conducted over a period of about 8-months and used a co-design approach involving people with dementia, their caregivers, and researchers from a number of domains. We adopted this approach to get meaningful insights regarding the participants' and other stakeholders' daily routines, their biographical background, their memories and social environment, their experience of using technology, and their attitudes and practices. Results

Research setting, study setup and participants

Part of a national research project in Germany, the study aimed to design and develop an ICT-based exergames system for people with early to mid-stage dementia, and was approved by the University of Siegen ethics board. The authors initially conducted semi-structured interviews and observations in different day-care centers to get insights about the everyday life of people with dementia. Afterwards, the system was designed and installed in three different homes and four day-care centers and regularly visited over a period of 8-months. The two settings were subject to specific empirical investigation. In people's homes the focus was upon ambulatory care. In the day care centres the focus was upon the use of stationary day care facilities. In each setting, we deployed the ICT-based system over the whole 8 months and asked participants to use the system and perform the training sessions on a regular basis. Training sessions usually lasted one hour.

We visited each day care setting twice a week to support and directly observe day care guests' and professional caregivers' interaction with the system. Here, training sessions were performed in groups of 4-5 participants. In the ambulatory care settings, where relatives were the caregivers, we also conducted bi-weekly visits. This was mainly done to provide space for the families to explore and learn the system together and create opportunities for them to reinforce or re-establish family structures. In total, we performed 80 visits with an average duration of one hour each. Trained research assistants carried out, moderated and assisted at each visit. They also conducted interviews with people with dementia and their relatives and observed their interaction with the system and other day care guests and relatives to learn more about their practices and attitudes regarding the exergames. Participants reported that they did training sessions using the system 2-3 times a week. All participants were experiencing behavioral changes associated with early to mid-phase Alzheimer and vascular dementia. We focused on 14 participants, aged between 72 and 89. 6 were female, 8 were male (see Table 2).

PN	Name	Age	Dementia stage	Setting
1	Mr. E.	89	Mild dementia	Day-Care
2	Mrs. Q.	76	Mild dementia	Day-Care
3	Mrs. T.	72	Moderate dementia	Day-Care
4	Mr. S.	86	Moderate dementia	Day-Care
5	Mr. K.	78	Moderate dementia	Day-Care
6	Mr. C.	82	Mild dementia	Day-Care
7	Mr. B.	85	Mild dementia	Day-Care
8	Mr. W.	79	Moderate dementia	Day-Care
9	Mr. H.	82	Mild dementia	Day-Care
10	Mr. H.	75	Mild dementia	Day-Care
11	Mrs. V.	75	Mild dementia	Day-Care
12	Mrs. K.	84	Mild dementia	Ambulatory and Day-Care
13	Mrs. H.	83	Mild dementia	Ambulatory and Day-Care
14	Mr. C.	78	Moderate dementia	Ambulatory and Day-Care

Table 2: Participants

Participants were excluded from the study if: (1) their dementia was beyond the moderate stage; (2) they were suffering from chronic diseases such as cardiovascular illness or cancer; and (3) their physical fitness was impaired such that they could not walk without assistance. Relatives were asked to self-report on the general condition, capabilities, and diseases of the participants. This was further confirmed by professional caregivers. In addition to the interviews with the participants, we conducted interviews with 9 professional caregivers or managers from day-care centers, 6 relatives and 2 experts from NGO´s before and after the system was used in different settings. All of them visited and participated in the group-based sessions or the training sessions at home on a regular basis.

To support the study a network was set up, including both the participants and their formal and informal caregivers. We wanted to examine how the system affected activities of daily living in people with dementia and their caregivers and, if such effects existed, whether they were significant in relation to the social lives and well-being of both groups. In the case of dementia, a key part of the complexity is the way the progress of dementia can lead to ongoing changes in living conditions. Through the network, we were able to involve other stakeholders from related disciplines and the public sector in the development of the ICT-based solution. So, the approach provided for open collaboration amongst a variety of actors, reflecting their different knowledge, interests, and aspirations, paving the way to a mutually tailored and appropriate technical solution (Eriksson et al., n.d.).

Data Collection

In terms of data collection, we conducted semi-structured interviews with the sample of 14 older adults with dementia and 9 of their caregivers. Interview questions concentrated on: their biography; daily routines, physical and cognitive resources; and the effects of dementia on their individual and social life. Participants were encouraged to elaborate freely upon these topics. All interviews were conducted face-to-face by trained research assistants. Each interview was audio-recorded, then transcribed. The interviews lasted 30 to 120 minutes and were supplemented by direct observation of participants' interactions with the system. Research assistants assembled additional observations and field notes after every group session in the day care settings. All of the data was supplemented by research notes that captured observations and reports of individual people's experiences of using the system across the day-care and home settings. Notes were also kept regarding exchanges with the participants via email and telephone. To triangulate our data we followed three strategies: (1) talking to relevant actors about the same topics at different times and levels of detail, (2) talking to different actors about similar topics, (3) discussing our findings within the project team, which included experts from the field of sports and nursing science, as well as experts from NGO´s.

Data analysis

The qualitative data from the audio recordings and field notes was analyzed using a thematic analysis approach (Braun and Clarke, 2006). Coders performed inductive analysis of the data transcripts using the software application MAXQDA and generated the main categories. Coding discrepancies were then discussed as a group and eliminated by adding, editing or deleting codes. The final codes covered categories relating to: user experience; perceived usefulness of the system; benefits and drawbacks of using the system; data privacy; trust and control aspects relevant to system use; impacts; motivations for using such systems; and requirements for integration into daily routines. Based on the coded data we then derived implications for further design and refinement of exergames for older adults with dementia.

System overview

An initial prototype was available, as stated, based on previous work which had focused on the system's effectiveness for improving health, its integration into daily routines and the contexts of use of a potential system for older users with respect to fall prevention (Gschwind et al., 2015; Ogonowski et al., 2016a; Vaziri et al., 2017a). Based on those insights, we re-designed the prototype to meet the special needs of people with dementia and report on the evaluation of its use and the development of application scenarios. In what follows, we describe the modifications and upgrades we made to the initial prototype.

Technical Infrastructure

The system consists of several technical components (see Figure 2). The technology is centred around a TV (4) so as to provide an easy and familiar route through which it can be accessed. Older adults tend to watch more television and use less ICT when compared to younger generations (Ijsselsteijn et al., 2007). The system runs on a mini-computer (1) that includes several exergames (2) and is connected with a MS Kinect (3) to detect the movements of the participant when interacting with the system. A male and female 3-D model and an underlying biomechanical model were provided for the Kinect-based motion detection. Recognition of the movements detected by the Kinect is reflected in their visual representation, providing comparable and measurable movement definitions and movement sequences (De Rosario et al., 2014).

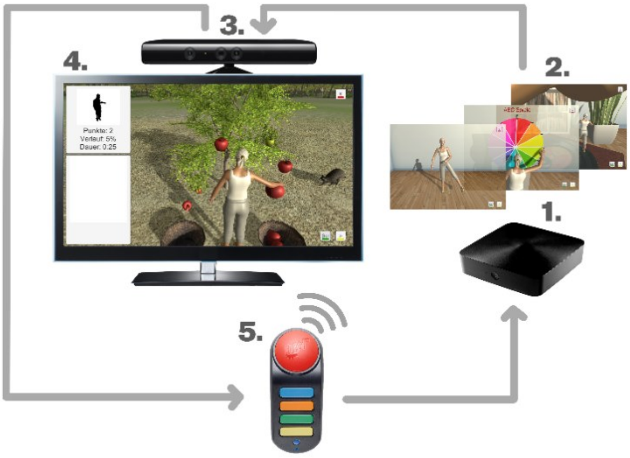


Figure 8: System overview

To simplify the interaction with the overall system, a PlayStation 3 Buzzer (5) was used. The Buzzer, with its big colourful buttons, is used as a simple input device during the games (e.g. to choose an answer during a quiz). The system has three different aspects, described below.

Training content

Exercises and games, as well as tests to measure performance, were developed and selected from the fields of sport science, sport gerontology and nursing science. The aim was to counteract the progression of dementia and to help people with dementia to remain as autonomous as possible, lessening dependence upon relatives providing care. The program includes exercises that are necessary for the execution of everyday activities (e.g. climbing stairs, carrying bags, and sitting to standing transfers).

Strength training and assessment

To strengthen the upper and lower limbs and muscles, established exercise programs such as the Otago-exercise-program were implemented [43]. The training includes exercises such as: knee extensors to strengthen the front thigh muscles; knee bends to strengthen the rear thigh muscles; sideways leg raises for the lateral thigh muscles; toe-stands for the calf muscles; elbow bends for the upper arm muscles: and front raises for the shoulder muscles.

Balance and coordination

The focus of the balance and coordination games is to solve percipience, balance, reaction and aiming tasks in a playful fashion. For instance, in the so-called "apple game" the participant has to harvest virtual apples from a tree and put them in the basket next to them. In a second game participants have to raise their knees in turn whilst walking through a park. In a third game they have to perform sideways and forward steps to hit moles.

Creativity and cognition

The creativity and cognition aspect was developed together with professional caregivers and therapists who work with people with dementia on a daily basis. These exergames cover a variety of games that combine movement and cognitive tasks. In the game "wheel of fortune" participants have to raise their hands and spin a wheel. Afterwards, they have to solve different types of tasks (e.g. letter games; mental arithmetic; classification and completion of rhymes, verses and poems; and remembering music titles).

Findings

In the following, we present findings in relation to the research question and connected categories, which describe the impacts and benefits for people with dementia and their caregivers using the exergames over a longer period of time. We report upon a range of matters here because long-term improvements in group dynamics, learning effects, and the leisure time available to caregivers can all feed into how a technology might be integrated into everyday life.

Impacts upon and benefits for people with dementia and caregivers

After just a short period of time, personally-related improvements in physical abilities, especially regarding balance and stability, were visible. Thus a professional caregiver from a day-care center said, that: „I think already, things that are significantly better are their balance and gait, which is somewhat more upright. [..] You can definitely say that the participants have benefited from the exergames. Activity and Motion is always good, it supports breathing, the musculature, but also balance. The exercises, as I saw, particularly improve balance, which will result in an improved stability and gait and therefore reduce the risk of falling. I can see a huge benefit for the participants."

One participant (Mrs C, 78 years) said herself that she liked to play the game "Hiking". When asked if she also liked to play "apple-picking" she explained that she couldn't get "so high anymore". Nevertheless, she noticed that the training "helped her a lot already" and she realised there was an improvement "in her whole body". When she was asked to describe the game "apple-picking" from memory she answered: "Yes, we always stood up, arms apart and then the figure appeared. As I said, around me there was then a yellow drawing and then you could pick the apples. It was always five to ten apples and around them there were also yellow circles. A golden circle, and then you had to put them into the basket." Ingrid, the daughter of Mrs. C, described her mother's experience with the system as follows: "My mother has the device [and] when using it, to do it, she used to shuffle most of the time with her feet, but over time she's got her feet up. Not right up yet, but at least so that she no longer grinds the ground. She has fun, especially the games apple-picking and skiing. She does 60 minutes on it in the afternoon and, well, she has a lot of fun." When asked if anything else had changed and whether Mrs. C seemed happier, Ingrid stated that her mother was "happy when she wins and when she picks apples. She picked less before but she has fun and it keeps her active."

Regarding whether the games helped with mobility, Mr. H's daughter, Silke, said: "yes…, I noticed an enhancement in his balance, he's more confident. If something is lying on the ground, he picks it up, I think this results from the apple picking-game… He also wanted to have a plan for what he could do in the household. I was really surprised. So he brings out the garbage, very conscientiously." When asked if anything else had improved as a result, Silke said: "Definitely his movements and his understanding of the whole context. My older son also plays the PlayStation. He [her father] didn't understand it. When my son said 'grandpa I'm going upstairs to play the PlayStation', he asked what he was doing. Now he knows it's the same as his system downstairs only with different games." Regarding any possible impact upon the physical performance, Ingrid observed about her mother that, "There's not so much she can do anymore. She couldn't raise her arm at all anymore, but since we've been doing the apple-picking, it's working again. She does have some pain but she wants to pick the apples." All of the participants were happy to be challenged not only physically, but also cognitively in the games, something that otherwise rarely happened. “Here the head is needed, but it‘s also asking that you move, and that’s what we need here" commented Mr. S after finishing an exergame. By challenging them, it seemed to be the case that the participants were finding new levels of self-confidence. When a task was completed or a correct answer to a question was given participants were visibly delighted, even making victory poses when an apple fell into the basket. Some even gave voice to their newfound self-confidence: “I can still do it“ (Mr C), “I think I don’t need the chair anymore“ (Mr B) and “Slowly we can do that“ (Mrs K).

Participants demonstrated increased motivation and ambition to improve themselves beyond their current physical constraints and were evidently pleased if they saw improvement. “I have problems with my right side but I’m doing it anyway“ (Mr H). “Yes, I’d like to start with the skiing because I’m bad at it” (Mr H). Thus, Laura, a professional caregiver, said “this is already a very positive effect, their self-awareness is enhanced… we can see that the participants are happier, more cheerful, more self-aware, and quicker after finishing the exergames.” When it came to motivational aspects of the system, Mrs. C trained at least twice a week, often more, sometimes even daily. In relation to this, Ingrid commented that “We take her to the Allgäu [famous holiday-spot in Bavaria], she has to lift her feet and needs to walk there. If she can’t do that anymore we can’t take her, so she’s motivated.”

Learning effects were also observed. Once the game was known, the tasks were executed quickly and easily. Learning effects were also visible when the exercises were performed more frequently, with certain tasks being recognized and remembered. Another participant, Mr. E, said after finishing one of the games “you need to do it a few times to understand it.“ The more often the participants played the games, the better they came to understand the exercises, and their execution and performance of the exergame-tasks improved. This is an important result for people with dementia where retention is not a given. Thus one of the professional caregivers, Astrid, was moved to comment: “we have especially also noticed that, despite their dementia, after the second or third time the participants are understanding it better.”

Relieving the challenge upon caregivers

Mr. H participated in the weekly training offered for groups in the day-care center he attended. He played exergames there on a regular basis, but he also had the opportunity to train whenever he liked at home. He said that he particularly loved to train with his grandchildren. Indeed, that was why he wanted the equipment at home. He also stated that he found playing the games fun.

Something important to note here is that playing the games was actively supporting relationships that might otherwise have been challenged by dementia. When we discussed with Mr H’s daughter, Silke, whether dementia was restricting what her father could do in his environment, she commented: “It’s not that progressed at the moment. What is bad sometimes is that he doesn’t know the names of his grandchildren anymore and in certain situations can’t use them. There are also many things that were said just the day before that he’s forgetting.”

However, to set against this, Silke stated that her father was using the system: “three times a week, but also with the (grand)children for one and a half to two hours. He keeps a note of their respective high scores and compares his with the grandchildren’s. They battle each other, it is going well.” An additional important outcome of this was that, because the game was being played at home and with the children, it was freeing up time for Silke herself as the primary caregiver: “By the way the game is also great for mothers. Hours of leisure time because the kids are playing together with grandpa”. We asked if Mr. H was interested in any hobbies. However, Silke’s response was that “Indeed, the playing is his hobby at the moment. They have three fixed days, for which he’s thrilled every time. He knows exactly that these are the days he isn’t in day care. I don’t play along anymore. I’d rather use the free time. So the kids and grandpa do it. In the meantime he can also turn it [the system] on all by himself.”

Social interaction and group dynamics

Enthusiasm was often a feature of the group conversations or when the participants were talking to university employees and not currently gaming. Participants in the day-care centre developed a strong sense of interpersonal relationships, saying things like “we do it as a group“ [Mr S during a day-care session]. Passive participants that weren’t currently involved in an exergame also, we noticed, applauded when somebody had finished a task. Mr. K captured the motivation they had to participate in the exercises as a group: “If I am in the day-care center, I am automatically also here in the exergame sessions. I always look forward to the group exercises.” As we noted with Mr H and his grandchildren, participants liked to compare their performances amongst themselves, recognizing the achievements of others, but remaining competitive and paying attention to who were the best players. Mrs. V, for instance, told us: “i can’t do it as well as Mrs. E“.

Participants often cheered, encouraged and helped one another. Fun and the group atmosphere were often cited as reasons to return to the practice units. “It’s more fun together, that’s why we’re here“, said Mr W. Michael, a care manager at one of the day-care centres, who regularly joined them for the exercises, noted several points about the composition of the group, the group-dynamic, and the motivation to participate that resulted from this: "Most [of the participants] get along with each other well. Since then a certain group dynamic has also developed, they [participants] have then also been trying to outdo each other with picking apples or the gates during skiing (laughs). That was quite interesting. Where you have to say again that they had fun doing something in the group. There was this sense of community, [...] you could already see that their body-language had improved and that the exercises were something special for them and that they had more self-esteem after playing." The group-setting atmosphere was cooperative, respectful and motivating. Steffi, a day-care center nurse, described it as being “cooperative during the exercise, because their dementia had different manifestations. One or another needed more support but it felt quite positive and open minded.” Karl, another day care manager said that, “not only has the communication between the participants enhanced, but also the communication amongst all of the day-care guests because of the exergames. The exergames and their content are an important topic in their daily discussions. This also has a very positive effect for the psyche and the self-confidence of the guests and participants.”

Integration and impact on the activities of daily living

When asked if anything had changed in the daily activities of the participants, Michael, the day-care center manager, answered, “yes, I would say so, because something has improved in their daily routines, for example in daily procedures like washing and bathing. But it’s important that the exergames be done over a longer period of time.” A variety of system problems affected the participants' experience with the system. Some of them became impatient if the system wasn’t working properly, because it was not given that they would understand what was going on. Mrs. Q, a participant from the day-care setting was confused and complained: “I would like to put the apple in the basket, not to stand around uselessly.” Another concern expressed in feedback related to the scope for using the system on one’s own. For instance, with regard to security and safety, Mrs. C, when asked why she didn’t train alone, answered: “I’m frightened. Well not really frightened, but I have a weird feeling. So, it’s better when there are two people than being alone.” In a similar vein, Ingrid was asked whether she was always there when her mother was practicing and whether that helped. She replied: "yes, clearly she can’t do it alone. In any case [it is a relief], before she just sat in the chair and watched TV and now she does this. This is really exhausting but she has fun. I find it very good that there is something like this. "

However, sometimes just having someone around is enough. Ingrid, for instance, added to her comments above: ”I sit on the sofa and she does it, she knows the procedures now.” It is clear that, to have a solid impact upon the activities of daily living, “long-term implementation” of the system is going to matter because short-term gains can rapidly slip away with dementia. Thus, the day-care centre manager Karl observed “the system has a positive effect but should be conducted over a longer period at a sustainable level so the positive effects don´t disappear so quickly.” Obviously, an important factor in integrating use of the system into people’s everyday lives is providing ongoing access to it. Whilst some did have the system at home, this was not uniformly the case. Some of the participants clearly wanted this. Thus, when asked “if you had the system at home, how often and how long would you do it?“, Mrs V replied, “three times a day for half an hour, it depends”. The day-care centre manager, Michael, also noted the benefits of self-sufficient exercise at home and saw the scope for it to have an impact upon people with middle stage dementia if they had already acquired a habit of using it: “an additional value [in terms of Mobility and ADL´s] for the patients could be added through activating the dementia patients, in the beginning stage but eventually also in the middle stage. The middle stage is possible, if in their biography they’ve already done something with movements and screens, so that they are not reluctant.”

Discussion

In the following section, we will discuss the results presented above regarding the individual and social benefits of using the exergames we have been describing. We will also consider the practical aspects of the study design and examine the limitations and challenges still confronting design and development in this space.

Social impacts and benefits for people with dementia and their caregivers

Our results illustrate that the use of the exergames system affected the social life and environment of people with dementia. We saw that social impacts took place on an individual and a community level during and after system use. People with dementia seemed to improve their self-confidence by using the system and were then able to execute daily life activities more securely. This was mainly shown by the re-establishment of previously impaired daily life activities, for instance picking up objects from the ground or taking out the garbage. In this context, results imply that some people with dementia in our study felt encouraged and capable to demand household activities again and regain social responsibility. These findings are in line with existing literature, suggesting that the use of exergames for mobility support may improve self-confidence and autonomy in people with dementia (S. Lauriks et al., 2007).

Further, we observed that the body language of people with dementia improved after using the system, for instance in terms of upright and confident bearing. This aroused attention among other day-care guests who did not participate in the study, encouraging them to ask about the activities, which led to further conversations amongst them all. Hence, social interaction, communication and the establishment of new relationships were facilitated by the group sessions. These findings and other studies suggest that the use of the system may improve well-being related aspects like self-confidence or autonomy and thus affect the social life of people with dementia (Mélodie Boulay et al., 2011; Férnandez-Calvo B., Rodriguez-Pérez R., Contador I., Rubio-Santorum A., Ramos F., 2011; Robert et al., 2014a; Weybright E., Dattilo J., Rusch F., 2010; Yamaguchi et al., 2011a). We also learned that the use of the system by people with dementia benefited their relatives. Here, we saw that grandchildren of people with dementia started to develop an interest in the system and its games. After a while, people with dementia and their grandchildren played the games together on a regular basis. Both, people with dementia and their grandchildren engaged intensely in playing the games together and thus opportunities for other relatives to follow activities in their own social lives were created, for instance reading books, meeting friends or going out for a walk.

In addition to the benefits for relatives, such intergenerational aspects also supported people with dementia in readopting social roles and further facilitated communication and interaction across different generations, for instance in the form of information exchange or knowledge sharing. These results and the existing literature suggest that intergenerational aspects may be addressed by such exergames and positively affect their social lives (Pinto-Bruno et al., 2017a). Finally, our study indicates that people with dementia enjoyed using the system in both the ambulatory and day-care setting. With respect to the day-care setting, we observed that day-care guests who participated in the study were keen on mutual experiences while using the system. Interviews with both caregivers and people with dementia suggested that the group sessions provided an atmosphere of cooperation, competition and support and created opportunities for group dynamics that increased their enjoyment. According to other studies, such positive experiences seem to be important to maintain social participation and to establish or corroborate social relationships. With respect to the ambulatory setting, we learned that the exergames promoted the reinforcement and reestablishment of family relationships. In this context, findings suggested that the system supported mutual experiences between people with dementia and family members, for instance by enabling cooperative gaming and exercising together with grandchildren on a regular basis. Observations and interviews indicated that such cooperative aspects helped people with dementia to regain or maintain social responsibilities and facilitated reintegration into familiar structures and respective social roles. In our study, it seemed that the system encouraged and enabled people with dementia to readopt part of their social and daily activities and develop more self-confidence in this regard. Related literature suggests similar findings, emphasizing the relevance of mutual experiences between people with dementia and family members in order to leverage positive effects on their daily lives (Ijsselsteijn et al., 2007; Katusic and Austin, 2014; Koeppe et al., 2003; Lahmann et al., 2014; S. Lauriks et al., 2007; Rosen et al., 2011). To summarize, in terms of social impacts and benefits of exergames, our study implies that continuous use of such systems may lead to positive effects, such as reduced dependence upon general care-activities and the improved well-being of both people with dementia and their caregivers. However, in order to create opportunities for continuous system use, it is important to integrate ICT-based systems into people with dementia's daily lives (Meiland et al., 2017).

Integration and effects on daily routines

With respect to daily life integration, results implied that while people with dementia used the system with their grandchildren, informal caregivers were able to follow up on leisure activities that previously were set aside. Based on our interviews and observations, we are confident that this positively affected the quality of life and well-being of informal caregivers. Related studies in this field suggest similar effects and illustrate that ICT-based systems and exergames may relieve the effect for informal caregivers (Peluso and Andrade, 2005; Schultz et al., 2014; Schulz and Sherwood, 2008; Silveira et al., 2013). Finally, we learned in the ambulatory setting that providing meaning to daily life activities seems to be a relevant factor for people with dementia when engaging with and exergames. In this context, participants set individual goals for themselves, for instance maintaining or improving their physical conditions by training with the system in order to participate in upcoming holiday activities, thereby giving meaning to their use of the system. Other studies support the relevance of meaningful application of ICT artefacts in daily living as key for successful integration into daily lives of people with dementia (D'Onofrio et al., 2017). Overall, findings in the ambulatory setting suggested that the integration of the exergames might positively affect existing relationships between people with dementia and family members and their daily life routines. With respect to the day care setting in our study, we found that moderated group sessions, where people with dementia used the system, evolved into a recurring activity and provided daily structure for them. This is reflected in a number of events where people with dementia could hardly wait to participate in these weekly sessions. During the interviews, caregivers mentioned that people with dementia also anticipated and hoped for sessions outside the weekly schedule.

Hence, we assume that the weekly sessions and the system were perceived as valuable to people with dementia and positively affected and enhanced their daily life routines and experiences in a sense that the combination of both, the system and the sessions, gave additional meaning to their everyday life. In terms of professional caregiving, we observed that at first caregivers supervised these sessions for security reasons. After some time, however, they stopped supervising the sessions as they noticed that people with dementia were strongly engaged with the system and didn’t need supervision any more. This freed up time for caregivers and thus provided opportunities to improve quality of caregiving for the remaining day care guests who did not participate in the sessions. In this context, our informal and professional caregivers recommended such exergames as a permanent feature at home and in day-care centers.

Limitations

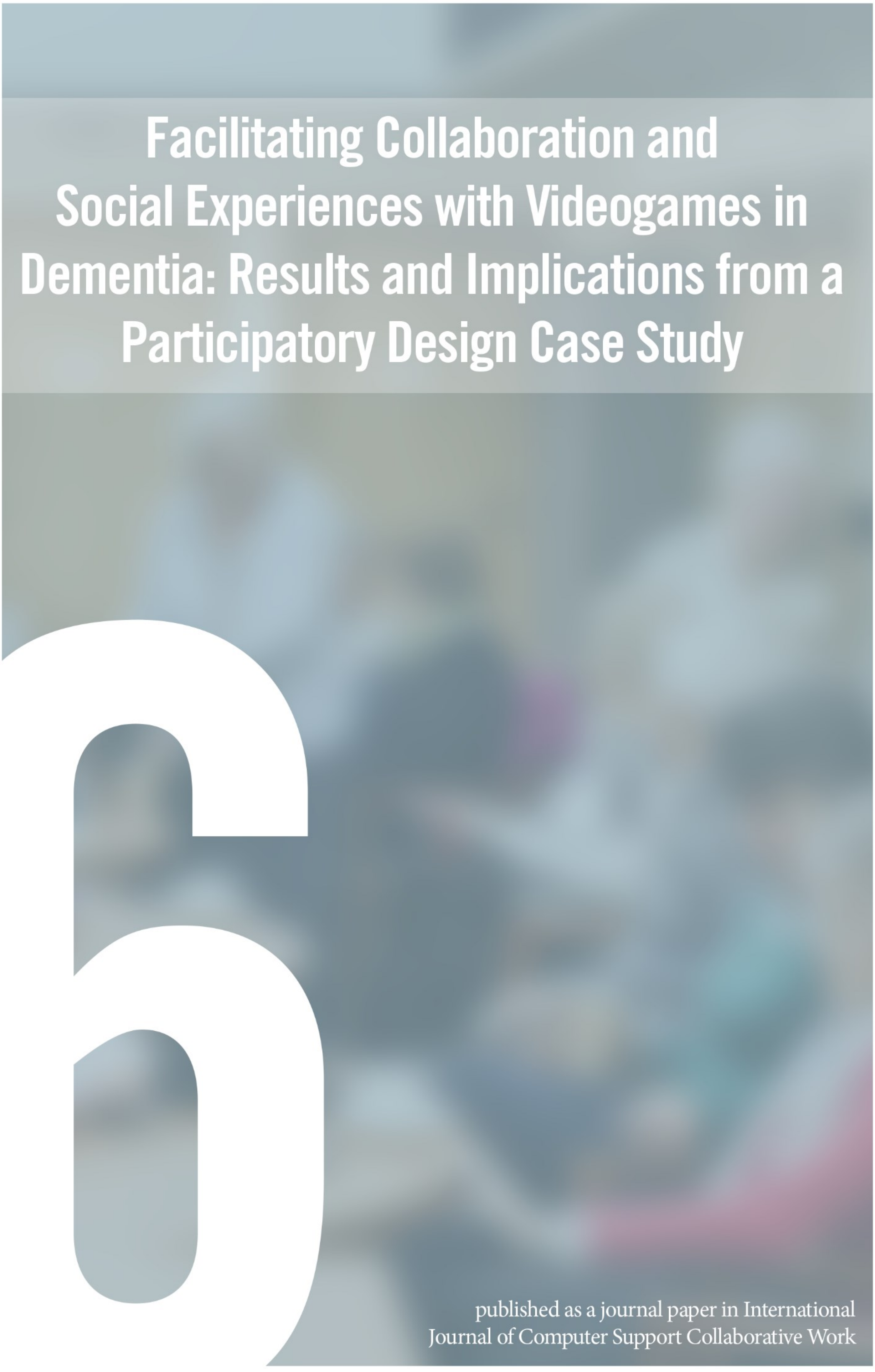
It should be noted that, in every setting, people had to struggle with different system issues over the course of the study. For instance, the Kinect-camera recognition was frequently disrupted by relatives, staff or roommates walking by in the background. Participants often also stood too close to the camera or groups stood with their backs to the camera, similarly making adequate recognition of the necessary movements impossible. Conducting qualitative research and designing exergames for and with people with dementia and their caregivers poses a variety of challenges. These include: recruiting the participant’s and their caregivers because of the stigmatized nature of dementia; daily living and the required efforts such as bringing people with dementia to day-care centers or practitioners; the emotional and physical challenge of care; and the difficulty of getting an “appointment” with the participants and their caregivers. During the recruitment phase there were problems finding participants who fulfilled the physical and health requirements. The help of a mediator in the form of a care institution was therefore introduced. Putting questions to people with dementia can also have variable outcomes.

Some participants were interviewed whilst exergaming and were not able to give meaningful and informative answers, largely because of the deterioration of their cognitive and communicative resources and capabilities. Often we found that relatives provided support for the participant during interviews, answering on their behalf. Clearly, our regular visits to the ambulatory and day-care settings, as well as our ongoing assistance throughout the whole research project influenced, and helped boost levels of use and motivation that might have not been present if the participants have been left entirely alone to get on with it for themselves. Participants and their caregivers often saw the home and day-care visits of the researchers as a pleasant opportunity for long conversations. Despite the heterogeneous sample of people with dementia who were finally recruited for the study, it should not be assumed that the findings necessarily reflect the broader population of people with dementia and their caregivers. The wider relevance of the study needs to be established through further research. The findings are therefore preliminary and not currently of measurable significance.

Conclusion

The results from the study have illustrated that serious exergames are able to support the self-confidence and well-being of relevant stakeholders and enable people with dementia to face the challenges of a self-determined and dignified aging with dementia. With respect to the individual and social impacts of the system, it seemed to re-facilitate certain aspects of an autonomous lifestyle, such as the mobility related activities of daily living, respectively promoting them and maintaining independence as well as offsetting deficits. The results also suggest that the system enhanced social interaction and invigorated relationships, improving empowerment to face the daily challenges of people with dementia in their social surrounding. It thus seemed to improve the quality of life and well-being of people with dementia and their relatives. For professional caregivers in day-care settings, the study suggested that implementing such ICT-based systems might support workflows and thus improve institutionalized quality of care. Much still needs to be done to build a wider corpus of empirical findings regarding how people with dementia can be supported by the use of these kinds of systems. We also need to further understand the most effective mechanisms for ensuring that this kind of support can be fully integrated into the everyday lives of people with dementia.

The aim of this exploratory study was to investigate the integration of a suite of ICT-based exergames into the daily routines of people with dementia and their informal and professional caregivers and to explore the social impacts and benefits of the system over a lengthy period of 8-months. A key feature here was the way in which the system was co-designed with relatives, professional caregivers and other stakeholders from related disciplines and the public sector. This process of open collaboration enabled us to reflect different kinds of knowledge, interests, and aspirations so that a mutually tailored and appropriate technical solution could be arrived at.



Facilitating Collaboration and Social Experiences with Videogames in Dementia: Results and Implications from a Participatory Design Case Study

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FACILITATING COLLABORATION AND SOCIAL EXPERIENCES WITH VIDEOGAMES IN DEMENTIA: RESULTS AND IMPLICATIONS FROM A PARTICIPATORY DESIGN CASE STUDY

Abstract

The prevalence of dementia and the need for associated forms of care is increasing rapidly. Information and communication technologies (ICT) have the potential to support collaboration and cooperation between people with dementia and their caregivers and to promote the independence, wellbeing and quality of life of all parties involved. In this context, we investigated the potential for an ICT-based videogame system to generate and facilitate social experiences for people with dementia and their caregivers. 26 people with dementia and their caregivers participated in a 16-month participatory design case study. The results suggest that collaboration and cooperation amongst the parties involved was increased by using the system. The study also revealed both positive and negative social experiences triggered by the videogame-based system. This article will report on these results and consider their implications for the future design of similar systems and their potential to further encourage collaboration and cooperation amongst people with dementia and their caregivers.

Introduction

The incidence of age-related diseases, such as dementia, has been increasing in recent years and this trend seems set to continue. As a result, healthcare systems face not only economic, but also social challenges including an increased need to support home and institutionalized care, to manage the dependency of people with dementia (PwD), and to deal with the increased workload of professional and informal caregivers. The increasing demand for care activities can often have a negative effect upon the wellbeing and quality of life of informal and professional caregivers and this can lead to a vicious circle of overload and diminishing health across an ever broader set of people (Chassioti, 2014; Coon and Evans, 2009; Schulz and Sherwood, 2008).

This being so, governments and society-at-large have a pressing interest in innovative concepts and solutions that can support care activities and the independence of PwD. Information and communication technologies (ICT) have the potential to deliver such support. ICT-based studies regarding PwD have shown that a range of technologies can promote enhanced interpersonal relationships, social wellbeing and physical performance for PwD and their caregivers (Chassioti, 2014; Coon and Evans, 2009; DeFina, 2013; Sugihara et al., 2015; Vaziri et al., 2016b). Amongst these possibilities, videogames have shown increasing promise (Legouverneur et al., 2011; Padala et al., 2012a). However, there is not a great deal of research that investigates the potential of such technologies with regard to promoting and reinvigorating social interaction and collaboration between PwD and other people in their social environment, such as relatives, informal and professional caregivers.

In this article, we present the prototype of a videogame-based system that was designed to support PwD and their caregivers in coping with the challenges of daily living and to encourage richer social interaction between them. Semi-structured interviews and observations in different day-care centers and households provided the necessary information about the attitudes and practices of the target group (PwD and their formal and informal caregivers) for design of the prototype system. Collaboration and social interaction amongst people in the target group who were using the system was then investigated over the course of a 16-month participatory design study, during which time the system was further refined and developed. On the basis of our results, we provide examples of a rich variety of ways in which such videogame-based systems can initiate collaboration and social interaction and thus generate positive social experiences for both PwD and their caregivers. We found in particular that the system promoted a powerful group dynamic in care facilities, whilst providing a significant opportunity for intergenerational interaction in homes that had previously been eroded. As a consequence, our study provides a new body of insights for this currently rather under-developed domain. Researchers and developers in both CSCW and beyond may then benefit from our results and reflections by taking forward the proposed implications, with the ultimate goal being ongoing improvements in the design of appropriate technologies for PwD and their caregivers.

State of the Art

Activity and Dementia

Living with dementia and its individual and social consequences can be positively affected by a range of different activities. Physical and cognitive activity, in terms of movement and exercises can postpone individual decline and help to slow down the development of dementia (DeFina et al., 2013). Different approaches to treatment can be pursued in order to decelerate the progress of cognitive difficulty and the loss of everyday capabilities (Colcombe and Kramer, 2003). Exercise programs have proved to be promising because they do not only target the symptoms of dementia but also other risk factors (such as cardiovascular disease or mental health). Studies have shown that exercises can improve physical abilities and hence the everyday capabilities of PwD (Kemoun et al., 2010). PwD face specific risks regarding their potentially limited mobility and their safety, for instance, the risk of falling. An associated decrease in activity tends to create a downward spiral, which is in turn connected to an accelerated reduction of physical activity. Along with this comes a reduction in their ability to perform everyday activities autonomously.

Outside of physical activity, treatments also seek to involve PwD in other things such as creative activities (drawing, craft, etc.), music therapy (singing, listening, dancing) and biography-oriented activities (re-enabling former hobbies and interests). It has been found that these can positively affect individual mood, social-emotional behavior, and communication skills, thus improving their psycho-social well-being. Allan and Killick (Allan and Killick, 2010) highlight the importance of communication and understanding its different facets, not only the spoken word but also emotional expressions, especially as, with dementia, these can change over time. Art and Music therapy has the potential to not only improve memory but also the happiness of PwD. It can reduce depression, a lack of life perspective and isolation, whilst increasing their ability to make decisions and their overall sense of hope (Hannemann, 2006; Sarkamo et al., 2014; Schmitt and Frölich, 2007). Participation in these activities needs to be seen in a nuanced way and Morrissey et al. (Morrissey et al., 2016a) argue that there is a particular need here for Experience-Centered Design, in order to create and further enhance these kinds of enriching experiences. In view of all this, technological solutions that tackle the debilitating effects of dementia and that seek to support PwD and their caregivers in everyday life need to consider not only physical activities but also cognitive activities and meaningful experiences, alongside aspects of the routine activities that are already present in their lives.

ICT and Dementia

Information and communications technology can play a key role in the development and integration of age appropriate assistance systems for health, safety, care and communication. These kinds of technologies can make an important contribution to the lives of older adults, people in need of care and PwD, not to mention their relatives, by making it possible to live an autonomous life in old age. However, setting aside matters such as technical implementation, conceptual design and economical use, there also needs to be reflection regarding how to keep track of a particular target groups' needs (Georgieff, 2008). Currently, only a few studies examine the use of ICT in relation to cognitive decline and the activities of everyday life (Pinto-Bruno et al., 2017a). Most interventions to date have related to areas such as: screening technology (to uncover possible symptoms); memory-aid technologies (to help people to remember things); health and safety monitoring (to keep older adults healthy and limit the risks confronting them); information sharing and tele-care (with the goal of using network technology to help caregivers in a potentially distributed fashion); and communication support and therapy (to support PwD by facilitating different kinds of communication) (for an overview here, see (Sugihara et al., 2015)). The majority of these interventions help PwD and their caregivers to cope with certain specific challenges without focusing on slowing down the cognitive decline that comes with dementia. Looking across all of the various studies and technologies available, a core concern is appropriation and the extent to which these interventions promote processes of individual and socio-cultural adoption (Silverstone and Haddon, 1996; Ylipulli et al., 2014). In relation to this, a study by Lazar et al. (Lazar et al., 2017b) investigated how technology might foster participation in digital social sharing by PwD, this being an increasingly important and pervasive aspect of daily life. However, amongst other things, they were obliged to conclude that a key problem with new sharing systems is that they miss a long-term perspective. Bringing about successful appropriation of a new technology involves consideration of people's personal and inter-personal needs and their expectations. Users need to be able to see the meaning and purpose of a proposed technology and need to be provided with ways in which to integrate the technology into the structures of daily life and their social environment. It has also been found that appropriation processes are strongly connected to people's biography and their former experience of using technology (Rogoff, 1995; Silverstone and Haddon, 1996).

Serious Videogames

Serious videogames are games that convey information, skills and knowledge in an entertaining way. In this regard, Baranowski et al. have shown that Serious Games can have a positive effect on health-conscious behaviour (Baranowski et al., 2013). A notable example of the integration of serious videogames into the daily life of older adults can be found in the work of Vaziri et al. (Gschwind et al., 2015; Vaziri et al., 2016c, 2017a). Here, older adults living independently at home were trained in front of their television to reduce their individual fall risk. The system was developed for exercise training sessions and fall risk assessment and incorporated discrete measuring technologies and adaptive assistance functions. A number of studies have shown that serious videogames for older adults can increase the efficiency and quality of their training without incurring any additional demands for care or nursing costs (Gschwind et al., 2015; Ogonowski et al., 2016a; Vaziri et al., 2016c, 2017a).

With regard to this, Gerling et al. [16] conducted a three-month study with 16 participants in two long-term care facilities. Their results suggest that “playing video games in the context of a weekly activity is enjoyable and empowering [but the game design should consider] the range of skills and abilities among older adults” (Gerling et al., 2015, p. 1580). In another medium-scale study by Smeddinck et al. (Smeddinck et al., 2015b), an exergame was evaluated over the course of five weeks with two groups of older adults. The results showed significantly increased autonomy and a sense of ‘presence’ amongst members of the exergame groups. Siriaraya and Ang (Siriaraya and Ang, 2014), meanwhile, have explored the long-term impact of 3D-based virtual worlds on people with dementia in care homes. They developed three prototypes that all used some kind of gesture control: a reminiscence room; a virtual tour; and a virtual garden. These three-dimensional worlds were tested with PwD residents of 80 years and over, their relatives, and their professional caregivers. The goal of the study was to design 3D worlds that took into account the needs of PwD and their relatives so as to enhance their quality of life. The results showed that the experiences and memories created within the virtual worlds increased the sense of self-worth of older PwD. The virtual worlds were enabling the residents to temporarily escape from their closed physical environment and were transporting them into a world of memory. As Siriaraya and Ang put it, the virtual worlds were a “sacred haven” that helped to preserve their memories (Siriaraya and Ang, 2014).

A related approach to serious videogames is gamification where different exercises, computer games and new technology are combined within some over-arching series of movement games. For designers focused on gamification the emphasis is not so much upon the development of games as upon using the basic mechanisms of games and the things that work well about them to enhance existing service offers and products (Freyermuth et al., 2013). In this vein, Padala et al. (Padala et al., 2012a) conducted a study in which older adults tested and trained with a Wii Balance board. Before the implementation, none of the participants could imagine using the system for exercise in their daily routines. However, after the first test-run, all of the participants were convinced to at least try it out at home. It quickly became clear that interaction with the new technology was generating significant enthusiasm. Even at an advanced age, participants were looking for challenges and wanted a ranking list to be incorporated so that they could see their results in relation to other players. Unfortunately, the levels in some of the games could be played through rather quickly and there was no overall increase in difficulty. In the absence of an ongoing challenge some of the initial enthusiasm started to dissipate. Nonetheless, the participants generally formed a very positive impression of the game and particularly enjoyed the fact that the game was designed to be played together with their grandchildren.

Collaboration and Dementia

Collaboration in relation to dementia is most often seen inside families themselves, which is where the majority of caregiving happens. However, it can also be found in the broader ecosystem around a person living with dementia, such as in the day-care center and amongst professional caregivers, nurses and medical doctors (Bowers, 1988; Duncan and Morgan, 1994). The role of day-care centers has been a particular focus in previous investigations. Brataas et al. (Brataas et al., 2010) showed how visiting day care centers could have a positive influence on people with mild dementia, stating that the “day care programme gave meaning in life” and, especially, that the “social and cultural activities gave meaning and offset feelings of loneliness and sadness and also stimulated cognitive functioning”. In a different study in Taiwan, Lau et al. (Alice Lau et al., 2008) focused on the role of family members after a loved one had moved into a nursing home. This study emphasized the need to sensitize healthcare providers to the family’s needs and to develop an intervention strategy whereby they could be a part of the caregiving process. Pashby et al. (Pashby et al., 2009) underscore the fact that “dementia care is a fluid process that requires flexibility, creativity, and adaptability as the disease progresses and related behaviors change”. In their case, they propose the need for a ‘sharing of experience’ between healthcare providers and family caregivers and suggest this could be supported by the use of technology. Schorch et al. (Schorch et al., 2016) present results from the development of a platform for informal caregivers that was designed to support their physical and mental care ability by enabling learning and orientations to care by facilitating close exchanges between formal caregivers, family members, and other informal caregivers. In their study the focus is upon how caregivers conceive themselves to be experts, the need for social support and how coordination and collaboration is accomplished with other stakeholders in the field. Our study follows on from these various approaches by conceptualizing ‘collaboration’ to be a holistic approach that includes all stakeholders around PwD. We would note here that, as collaboration relevant to PwD happens between many parties, including family members, informal and formal caregivers, and interventions should involve all of them in the design process.

Research Question and Contribution

Inspection of the above literature reveals that there is currently a lack of studies that examine the collaborative effects of technology and that provide recommendations regarding the design of appropriate videogames for people living with dementia. A particularly notable absence from the literature is anything that focuses upon the development of systems that integrate understanding from across the diverse disciplines that have an interest in dementia care, e.g. sports science, cognitive training and those who are involved in both providing and designing for the everyday treatment of PwD. We present here results from a design case study (Wulf et al., 2011) that describes how the process was pursued across the various steps of exploring, evaluating and designing an ICT-based platform. In particular, we illustrate the related individual and socio-collaborative impacts and benefits of a videogame-based assistive system that was designed to support PwD and their caregivers. The article specifically seeks to address the following research questions: (1) How should videogame-based activities be designed to positively affect individual capabilities and the social environment of PwD and their caregivers? (2) What are the general and specific factors involved in designing videogames for PwD and their caregivers that might encourage their long-term use in a sustainable fashion? In the discussion we provide a number of important insights relating to these questions that became manifest through our analysis of the results.

Methods

Study Design and Approach

To develop ICT-based interventions for PwD and their carers, it is essential to involve potential end-users right from the beginning. It is also important to understand the relevant environment and respective contexts they move through and how they are already interacting with technologies and have integrated them into their daily lives. As mentioned above, this study was formulated as a design case study, much as this was originally articulated by Wulf et al. (Wulf et al., 2011). In principle the approach consists of three phases: (1) a pre-study that involves empirical analysis of existing individual and social practices in a specific field; (2) design of innovative ICT-based artefacts related to the findings from the pre-study; and (3) investigation of the interaction with and appropriation of the designed technical artefact over a longer period of time (Wulf et al., 2011).

In our own case, we explored in the pre-study (see Figure 1) the existing practices, organizational and social perspectives, and individual and social needs and challenges confronting PwD in their everyday social surroundings. This involved both semi-structured interviews and observations of daily activities in different day-care centres and households to get meaningful insights about the everyday life of PwD. We also conducted interviews with informal and professional caregivers as well as other stakeholders from related disciplines, including practitioners, therapists and experts from the Alzheimer Society. Right from the outset, then, the approach enabled an open collaboration amongst a variety of actors, reflecting their different knowledge, interests, and expectations.

In a second, iterative step, we designed and deployed a prototype system in day-care centres and ambulatory care settings, where PwD and their caregivers regularly interacted with the system over a course of 12 months. The initial prototype had been developed on the basis of previous work (Gschwind et al., 2015; Marston et al., 2015; Ogonowski et al., 2016a; Vaziri et al., 2016c, 2017a) for older adults in general with respect to fall prevention. For this deployment, the system was adjusted to the needs, problems and expectations relating to PwD that had been identified during the pre-study. Throughout this phase the functioning and efficacy of the system was continuously assessed across the different settings, with it being ongoingly re-designed, refined and extended to reflect insights arising from our own observations of its use and feedback from the PwD and their formal and informal caregivers. We proceeded in this way in order to examine the potential of the system for all of the relevant stakeholders. In particular, and in keeping with a participatory design approach, we were keen to involve PwD and their caregivers as co-developers, drawing upon their different bodies of knowledge, interests, and aspirations as both the research and system evolved.

There followed a short period of re-design where insights arising from the main design study were assimilated and taken on board in order to develop a more ‘finished’ prototype. Then, in a third and final step, we evaluated the system over a period of 4 months. For this, we deployed the system in a different set of households and day-care centres. As we were working in different settings, we needed to collaborate very closely with the care-institutions and the participants, attending the day-care centres twice a week, which included conducting training sessions, and visiting the participants in their homes on a regular basis (1-2 times a week). The purpose of this final phase was to arrive at a concrete understanding of what appropriately tailored technical solutions for the target group (PwD and their caregivers) will need to look like as other such systems are developed in the future.

In the results we will be discussing in this paper, we will be focusing on the latter 16 months of the study, where the prototype system was deployed and iteratively refined, with a particular emphasis upon the findings coming out of the last 4 months of the study when the design of the system had largely stabilized.

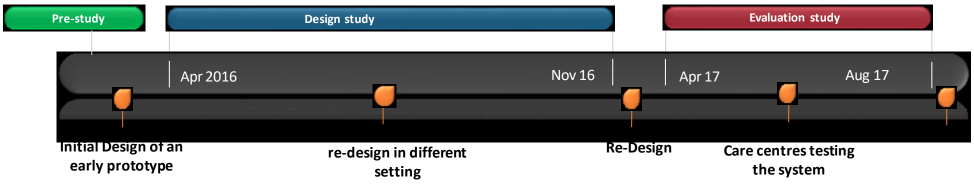


Figure 9: Timeline

Participants and the Settings

Overall, the study included 26 adults with early to mid-stage dementia (as confirmed by medical professionals) who were aged 65 years and over, including 6 informal caregivers. Ethical approval was given by the ethics committee of the University of <name>. The inclusion criteria were that the participants should have frequent access to a high definition TV with a HDMI port, located in a room with at least three square meters of space in front of the TV, so that they would be able to use the system without risk of injury. To minimize the risks during use and to ensure the game was performing correctly, sessions were monitored by a referee (a relative or caregiver). No financial compensation was offered to the participants.

PN	Name	Age	Dementia stage	Setting	PN	Name	Age	Dementia stage	Setting
1	Mr. E.	89	Early dementia	Day-Care	15	Mrs. H.	78	Early dementia	Ambulatory Care
2	Mrs. Q.	76	Early dementia	Day-Care	16	Mrs. T.	72	Moderate dementia	Ambulatory Care
3	Mrs. T.	72	Moderate dementia	Day-Care	17	Mrs. Z.	78	Moderate dementia	Ambulatory Care
4	Mr. S.	86	Moderate dementia	Day-Care	18	Mr. K.	85	Early dementia	Ambulatory Care
5	Mr. K.	78	Moderate dementia	Day-Care	19	Mr. R.	82	Mild dementia	Ambulatory Care
6	Mr. C.	82	Early dementia	Day-Care	20	Mr. C.	75	Mild dementia	Ambulatory Care
7	Mr. B.	85	Early dementia	Day-Care		**Name**	**Age**	**Relationship**	**Setting**
8	Mr. W.	79	Moderate dementia	Day-Care	21	Mr. H.	73	Husband	Ambulatory Care
9	Mr. H.	82	Mild dementia	Day-Care	22	Mrs. T.	23	Granddaughter	Ambulatory Care
10	Mr. H.	75	Mild dementia	Day-Care	23	Mrs. Z.	52	Daugther	Ambulatory Care
11	Mrs. V.	75	Mild dementia	Day-Care	24	Mrs. K.	82	Wife	Ambulatory Care
12	Mrs. K.	84	Mild dementia	Ambulatory and Day-Care	25	Mrs. R.	80	Wife	Ambulatory Care
13	Mrs. H.	83	Mild dementia	Ambulatory and Day-Care	26	Mrs. C	76	Wife	Ambulatory Care
14	Mr. C.	78	Moderate dementia	Ambulatory and Day-Care					

Table 3: Participants

Data Collection and Analysis

Over the course of the deployment (design- & evaluation-study) of the system, we conducted observations and semi-structured interviews with the participants to understand their existing practices and to uncover the various technological, organizational and social perspectives of all the relevant parties. Here, we focused mostly on the collaborative aspects and social experiences of PwD and their caregivers while using the system and whether these were positive or negative. Each interview lasted between 30 and 120 minutes and was conducted by a research team consisting of a more experienced researcher with a background in nursing and social science and a research assistant who was currently being inducted into the research practices adhered to by the team. The qualitative data consisted of audio recordings and field notes gathered over the course of the interviews and observations. This was analysed using a thematic analysis approach (Braun and Clarke, 2006). Based on the transcripts, researchers performed an inductive analysis of the data, coded it, and generated a series of main categories. Coding discrepancies were discussed and eliminated by adding, editing or deleting codes, according to the outcome of the discussion.

It is worth stressing that two kinds of settings were subject to specific empirical investigation. One of these was the ambulatory care that was executed at people's homes, the other was the stationary day-care facilities, where the PwD are guests for the day, returning home in the afternoon. Overall, the day-care facilities were visited by the research team about 120 times, mostly for the purposes of conducting moderated group sessions. These visits also included assisted training sessions with the PwD and their caregivers that lasted about 1 hour. During the moderated group sessions, we observed how participants interacted with the system and how collaboration and social experiences were facilitated by its use. With respect to ambulatory care settings where relatives performed care activities, we undertook weekly visits and offered to come more often if necessary. The focus here was upon providing a space for the families to explore and learn the system together. For the ambulatory settings we conducted 44 visits to the households, with an average duration of about one hour.

System Overview

The system consists of several technical components (see Figure 2), organized as follows: a mini-computer (1); with several videogames (2); that are displayed on the TV (4); which is connected to a MS Kinect (3) to detect the movements of the participant when interacting with the system. There is, additionally, a set of levels (7) associated with each videogame, providing more than thirty levels overall. After playing the basic levels, the degree of difficulty increases and more dual and cognitive tasks appear. The participants have to play a "daily training schedule" to proceed in the system and reach the higher levels. The participants are given 4 or 5 videogames, which start automatically according to their individual training plan. Outside of the daily training, players can also choose to play the games on their own in “free game mode”. The system is connected to a cloud system (8) that is used as a backend information platform for creating users, keeping track of the achieved results, initiating training schedules and detecting level progression. To simplify the interaction with the overall system during the study, a PlayStation 3 Buzzer (6) was used as a navigation tool and input device during the games (e.g. to choose an answer during a quiz). The system has three different core videogame elements: 1) movement games and assessments; 2) coordination and balance games; and 3) cognitive and creative activities.

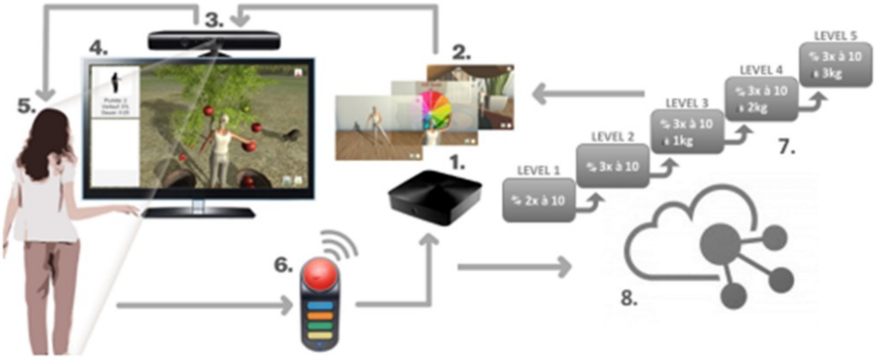


Figure 10: System Overview

Training Schedule

The training schedule was designed with respect to different disciplines (sports- and movement gerontology and nursing science), but also according to identified needs and recommendations from involved interview partners and caregivers, who sometimes suggested implementing games with a focus on music, biography and/or the creative activities already established as a part of the PwD’s routines. The system includes exercises that are necessary for the execution of everyday activities (e.g. climbing stairs, carrying bags and sitting to standing transfers). The level structure is controlled by the individual training schedule. After a player reaches the minimum number of points required to complete a level, the level increases (Figure 2, feature 7). At the same time, and based on the pre-study recommendations by experienced caregivers and therapists, each level can also be maintained, raised or reset without the player receiving any demotivating notifications. The system also gives you the ability to play previously completed levels, making it adaptable to a user's daily condition or their wish to re-play parts of their favorite games. The system was designed for the games to be played in single player mode, meaning that only one person is detected, even though the Kinect camera can, in principle, recognize more than one. However, other people could observe the different games and perform the exercises if they wished, though their movements were not detected by the system itself.

Strength Training and Assessment

The physical training is divided into strength exercises and a measured performance assessment (Figure 3). The strength exercises focus on lower and upper limb muscles, which are important during functional movements, walking, and recovering balance. They include seated knee extension, standing knee flexion, standing hip abduction, and toe raises. The strength exercises progress through increasing levels of difficulty and an increasing number of repetitions. The assessment feature measures physical performance with tests for balance, lower limb strength, and hand and step reaction times. It includes semi tandem, near-tandem, and full-tandem balance tests, where participants are asked to hold a stance for 30 seconds without moving their feet. The hand and step reaction time test shows how fast participants can react, if a signal lights up. There is also a strength test that includes a sit-to-stand activity.

Figure 11: Strength exercises (including upper and lower limb training) and assessment

Balance and Coordination Games

The focus of the four balance and coordination games is upon providing percipience, balance, reaction and aim tasks in a playful fashion. (1) The walking game (see Figure 4, a) requires that a player lifts their knees to a specified height to move forward (e.g. by running on the spot). In higher levels, more and more dual tasks appear, for example bumblebees fly towards the players and have to be avoided by shifting the body sideways. Flowers and cacti also appear at the wayside and have to be either collected or avoided. To collect the flowers the player has to stretch out an arm as they walk past. (2) In the apple-picking game (see Figure 4, b), the primary objective is to increase or maintain a player's radius of movement in their upper extremities. The goal-oriented stretching and grasping of virtual apples helps to maintain a users' ability to face everyday tasks (preparing food, grabbing something above their head, or washing the upper body or head). Players reach for apples in the trees with their arms or hands. A ripe apple has to be picked and collected in a basket, which is placed next to the player. Special apples are visually recognizable (shimmering gold or flashing). The player stretches an arm in its direction and picks the apple by lingering over the apple for a short time with their hand. They then move the apple in their hand towards the basket. (3) The airplane game (see Figure 4, c) focuses on mobilizing and maintaining upper-body flexibility. In higher levels the movements are coupled with small additional cognitive tasks to promote coordination and strengthen cognitive attention. The player steers a small plane through a set course by leaning the upper body to one side or the other, moving the plane through gates on the water and in the air. (4) In the game 'hit the moles' (see Figure 4, d) the player stands in a garden. Single moles emerge from mounds, one after another, intending to destroy the garden. By stepping with one foot on a mole as it appears, the animal is expelled and the garden is saved. The player then has to return to their starting position until the next "troublemaker" appears.

Figure 12: The four different balance and coordination games

Creativity and Cognition Games

The creativity and cognition aspects of the videogames were developed together with professional caregivers and therapists who work with PwD on a daily basis. These videogames cover a variety of games that combine movement, creativity and cognitive tasks (see Figure 14).

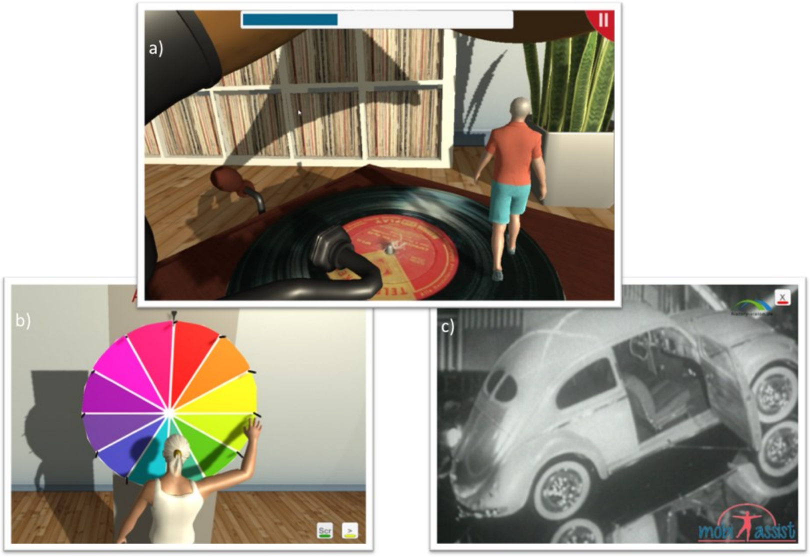


Figure 13: Creative and Cognitive Games

(1) The music room (see Figure 14) is about strengthening and improving endurance in the lower extremities. This playful running exercise takes place in a virtual setting on a spinning vinyl disc. The player acts as the needle on a vintage record player and can play previously selected pieces of music by walking. If the player stops or walks too slowly, the volume of the selected track decreases until the song stops. (2) The wheel of fortune (see Figure 5, b) strengthens memory and knowledge through a quiz. Various topics are addressed, including music, proverbs, everyday items, animals, objects, rhymes or math problems. The topics are selected via colored fields that represent the different categories. Players can interact and start the game by grabbing one of the outer pins with their hand and spinning the wheel. The quiz game is primarily about providing the cognitive training needed for everyday tasks. The 225 questions serve to strengthen skills such as recognizing and naming everyday objects or about recovering and communicating memories, especially in a linguistic form, with increasing degrees of difficulty. (3) The focus of the movie theatre game (see Figure 5, c) is mainly about making memories manifest and initiating discussions about the presented content. The movies are automatically retrieved and presented by the system and can therefore be understood as a communicational gateway to memories and a starting point for elucidating biographical information, rather than as an activity to increase physical fitness.

Results

Using a thematic analysis approach, several themes emerged during the process: the context of collaboration and cooperation; positive social experiences; and negative social experiences. In the following, these themes will be used to structure the results of the study, illustrating how the videogame-based system increased the range of contexts in which collaboration and cooperation might occur amongst PwD and their caregivers and the social experiences that ensued.

Figure 14: A participant interacting with the system

Collaboration and Cooperation

Participants in the day-care centers developed a certain group dynamic and a sense of interpersonal relationship when playing the games, which strengthened their collaboration as well as their enthusiasm and motivation. The social collaboration during the group sessions that were moderated by the research team was a major reason for participants to continue their participation in the sessions, since they often encouraged and helped one another and thus created a cooperative, respectful and motivating atmosphere (see Figure 6). Participants developed a strong sense of relationship in terms of "we do it as a group", as quoted by a participant. Passive participants that were not involved actively in a videogame applauded when somebody else finished a task. Further, a participant from the ambulatory care setting expressed his motivation to participate in the exercises, as they were conducted in groups. „*If I am in the day-care center, I am automatically also here in the game sessions. I'm always looking forward to the group exercises."*A nurse from a day-care center described the atmosphere as being "*Co-operative during the exercise. Due to the dementia having different manifestations, one or another needed more support, but [it was] quite positive and open minded*." One of the day care managers said:

> *"…not only is the communication between the participants enhanced, but also the communication between all the day-care guests because of the videogames. The videogames and their content was an important topic in the daily discussions. This was a very positive effect, for the self-confidence of the guests and participants and the communication of all the day-care guests."*

A professional caregiver stated "I believe that this cooperation and interaction is good for a group as well, if they cheer each other on and give each other positive feedback." This was expanded upon by a care-worker from the social services, who said that:

> *“I know that a couple of our day-care guests have always made an appointment or have agreed to do something together and then said ‘Today, the university is coming back. So, before we go for a walk or before we lie down we will join the game group.’ They always came together to ask together. So that connects already*.”

A care institution manager of a day-care centre who regularly participated in the sessions also reflected, with respect to the group dynamics and the motivation to participate:

> "*most [participants] got along with each other well. Since then a certain group dynamic has also developed, the [participants] have then also tried to outdo one another with picking apples (laughs). [...] There is this sense of community, the three participants we have chosen here to do the gymnastics’, you can already see that they have improved their body language and that the exercises are something special for them and that they are more self-aware after playing.*"

The findings indicate that PwD enjoyed using the system in both the ambulatory and day-care settings. Many participants in the ambulatory setting with the game equipment at home used the opportunity to connect with their grandchildren by playing the games with them. This actively helped to strengthen relationships that might otherwise have been challenged by dementia. Hence, this collaborative and intergenerational synergy supports people with dementia in readopting eroded social roles and facilitates communication and interaction across different generations. Our observations and interviews indicated that such cooperative aspects also helped PwD to regain or maintain social responsibilities and aided their reintegration into familiar structures, including ordinary daily routines and typical social activities.

It was almost always the case, of course, that the participants were using the system with someone, be they family members or professional caregivers. This established a common activity that was practiced quite regularly together. Mrs. T., for instance, said "We always played together". Both sides had a lot of fun, which convinced Mrs. T.’s granddaughter to play more games with her grandmother in general. Mrs. T.’s household even documented their use of the system and the results after each session (see Figure 7), continuing to keep track and follow up on their favorite games 5 months after the official evaluation phase had ended (up until January 2018). On each of the notes the participants described what they had played during the day and what they had achieved in terms of activities and games, even noting the level they had reached. They also wrote down any questions that arose when playing, such as “what should I do with the balloons when playing the walking game?”.

Donnerstag 27.07.~~200~~ 2017
Glücksrad Stufe 1
Ratequiz konnte nicht gespielt werden,
da die Technik nicht funktioniert hat.
Arme beugen Stufe 10
Arme heben Stufe 10
Knie strecken Stufe 10

Donnerstag 2.11.2017
Beine heben
Knie beugen
Maulwurf trampeln
Wandern im Wald
was muss man mit dem Hirsch und den
Luftballons tun.

Montag den 22.01.2018
Beine heben
Knie beugen
Beine strecken
Alltagsquiz
Maulwurftreten
Raterunde
Glücksrad
Juchhu wir haben gespielt, habe

Figure 15: Hand-written records kept for one of the participants

Another dimension here is that the system can offer a form of relief to informal caregivers by allowing them the opportunity to engage in leisure activities that would otherwise have been set aside. This, too, provides a common basis for communication and interaction. Thus the system had a positive effect upon the quality of life and well-being of informal caregivers as well. The daughter of one participant stated that her father was using the system:

"*three times a week and also with the (grand)children for one and a half to two hours. The respective high score is noted and compared with the grandchildren's ones. They battle each other, it is going well*." However, the daughter also commented upon the way in which the situation at home changed after the videogames were deployed:

> "*The game is by the way also great for mothers, hours of leisure time because the kids are playing together with grandpa*". Overall, our 16-month study revealed that video-game-based systems have the potential to generate collaboration and cooperation contexts and facilitate the engagement of all parties affected by dementia.

Positive Experiences

Informal and professional caregivers reported that they noticed the positive emotions and expressions being exhibited by PwD while using the system. For instance, playing music or asking questions their biography clearly evoked positive memories for them. One participant, Mrs. T., was reminded of her husband when talking about the music game. She said that she always "*enjoyed listening to her husband*". When it came to asking her specific questions about this, her associations with the music became apparent. She said: "*When I think about music, I think about my husband, who played a nice instrument."* More generally, completing a task in the game as well as giving a correct answer to a question delighted the participants, increasing their ambition to go yet further and stretch beyond their current constraints. In interviews with care-workers from the day-care centers another important point was raised. The positive personal and group-based feedback that people received by using the system played a major part in initiating their personal and emotional experiences. When they gave the correct answer to a question they felt empowered and it provided them with a chance to be good at something. This, in turn, strengthened their self-confidence and made them feel good about themselves. One caregiver said: "*Well, I see the system and its effects as an enrichment to their [PwD] daily life. The system enables a positive engagement, they have variety in their individual and group activities, they have guidance.*"

We additionally observed that learning effects began to set in after a while, especially when they were using the system frequently. This also gave them a sense of achievement. We found PwD actively expressing pleasure about their enhanced understanding of using the system and their improved personal performance in games. In addition, participants often cheered up, motivated and helped each other. Fun and a pleasant group atmosphere were important indicators to convince participants to return to the game sessions. „It is more fun together, that's why we're here", said a participant from a day-care center. From a professional caregivers' perspective, integration of the system allowed for more flexible time management. Only the initial group session required supervision by professional caregivers for security reasons. After that, no further supervision was necessary by the professional caregivers so, once the participants were left to be guided by just the researchers and had started to strongly engage with the system, they began to interact with it independently. In this context, a professional caregiver explained that: "we saw here the opportunity for the participants to define themselves through the system and to develop the ambition to be good at something and to receive feedback here as well. They enjoyed it and it gave people with dementia a lot of fun, which is not always easy, and I find that much more important and worth more than anything else."

Due to such positive experiences, group sessions became a recurrent event in the day-care centers, with participants regularly engaging with each other and having fun together. As a result, one representative of a care-institution expressed a wish to fully integrate the system and its games into their daily schedule of group activities, because the PwD were enjoying using the system so much. Of particular note is the way in which music seemed to be an essential driver for their positive experiences. As soon as the system played a song, the participants started to sing along and cheer. They also enjoyed clapping to the beat of the music and would invest their participation with evident emotion. Both the actual players and the spectators enjoyed the games, commented positively and would join in by singing along. An important point here is the way in which the music also encouraged PwD to move with the rhythm.

Negative Experiences

Having noted the positive aspects of the system for collaboration and the fostering of social experiences, it is important to also examine the negative aspects of what occurred. In view of the target group and the application context an obvious source for negative experiences relates to technical issues and malfunctions. For instance, the concept of an avatar sometimes proved too difficult or too abstract for the participants to understand. PwD occasionally perceived the avatar to be an instructor who they then expected to demonstrate tasks. This resulted in an incorrect execution of the games, sometimes leading to significant frustration. One participant, for instance, complained that “He (the avatar) doesn‘t do anything anymore.“ In general, the variety and complexity of system problems and malfunctions, largely attributable to it being a prototype, had a definite negative affect upon the participants' overall experience of using it. Some participants became impatient when the game-mechanics did not perform properly. One 72-year old lady in a day-care center became notably confused and exclaimed “I would like to put the apple in the basket, not to stand around uselessly“. Other participants were quite critical of one another: “He [the active player] doesn´t understand this. You have to do take down your arm. Take down your right arm. He [the active player] doesn´t understand this.”

In general, we observed that participants who were watching someone else play the games, could become rather impatient with the current player and express their distraction verbally by saying things like “we told you to take the other answer”. In some sessions, the participants told the researchers that they felt “like a candidate in an exam because of all the other surrounding people”, which was onerous for them. They felt a lot of pressure and some of them began to associate negative experiences with using the system in a group. There were also instances of participants refusing to use the system without being guided and encouraged by members of the research team. The wife of one participant told us “I've tried everything, and I cannot change it. The next day already. No one was there and I tried to motivate him to use the system. After encouraging him several times to use the system he screams at me or just leaves the room. He cannot be motivated to do anything. So, then that does not work because he gets angry.” In fact, her husband only seemed to be motivated to engage with the system when the research team was around. We also observed that users sometimes experienced technical issues with the Windows Kinect that impaired their experience. For instance, the Kinect would sometimes have issues with recognizing a player, depending on the light incidence, their clothes, or the setup of the furniture in their apartment. A common outcome of the camera failing to recognize them was frustration.

Discussion

The rationale of the research presented in this article was to identify the potential of videogame-based systems to promote collaboration and social experiences among PwD and their caregivers. This prompted us to collect qualitative data about the deployment of prototype system in home and day-care settings. In the following, we examine the results presented above and put them into perspective against the existing literature. By doing so, we will illustrate how our results add to what is already understood about the collaborative and social potential of videogame-based systems.

Collaborative Aspects

The findings suggest that participants in our study experienced enhanced levels of social collaboration and that, on balance, the system had a positive impact upon the lives of PwD and their caregivers. By integrating the videogame-based system into their daily lives and work routines participants in the study found that the relationships between them had been strengthened. The results also demonstrate clear intergenerational effects, with the system standing as a resource for certain kinds of social responsibility and social interaction to be regained by PwD. Particular aspects of these findings have also been reported in other studies (Melodie Boulay et al., 2011; Férnandez-Calvo B., Rodriguez-Pérez R., Contador I., Rubio-Santorum A., Ramos F., 2011; Robert et al., 2014a; Weybright E., Dattilo J., Rusch F., 2010; Yamaguchi et al., 2011a), but there has never been a thorough examination of them in the context of a suite of exergames that have been specifically designed and evaluated for use with PwD and their carers. Something that came to the fore in both settings is that the key factors influencing sustainable use, collaboration and social interaction are the ways in which a system is designed and evaluated over a longer period of time together with the various stakeholders, in this case the relatives, professional caregivers and other involved parties. By using a design case study approach, we were able to reveal aspects of collaboration and social experience that added to the existing body of knowledge and affirm the potential role to be played by videogame-based systems in the context of care for PwD. Thus, the process enabled us to incorporate, design for and reflect diverse needs, problems and expectations, leading to the development of a practice- and experience-based suite of exergames that can initiate social collaboration and help PwD and their caregivers to face the daily challenges they encounter in their social surrounding. As a result, the study participants found the system meaningful and, more than this, showed that they were able to understand and learn enough of the concepts relating to playing videogames for them to be able to contribute to local collaboration and fulfilling social experiences. In addition, associated informal and professional caregivers and external stakeholders perceived an added value in the system, which may have a positive impact upon its future appropriation (Gonzalez-Palau et al., 2013; E. Karlsson et al., 2011; Rosenberg et al., 2012). The system brings together the development of physical and cognitive resources in PwD, but also supports and facilitates improvements in social experiences and collaboration across ambulatory care and day-care settings, not only with regard to PwD, but also for relatives, informal and professional caregivers.

Positive and Negative Experiences with the System

Our findings also illustrated that effective comprehension of the highly individual needs and requirements of PwD and their relationship with their social surroundings requires the involvement of all stakeholders in the process of developing and evaluating the impact of videogame-based systems. It was clear across both, the ambulatory and day-care contexts that the collaboration and, especially, the positive social experiences being encountered by the participants, was supporting and encouraging appropriation of the videogame-based system. However, a variety of negative social experiences were also reported, covering matters such as interaction with the system, personal misapprehensions and inter-personal frustrations. It needs to be borne in mind that existing family issues are not at all going to be solved by deploying a videogame-based system. Indeed, on some occasions it may actively aggravate them. In that case, it is important to also consider the potential for negative experiences when deploying such technologies. Furthermore, when difficulties with use of the system do arise (in both technical and social terms), these need to be understood as lessons learned regarding how future iterations of the technology may need to be adapted.

The results of our study indicate that these kinds of innovative technologies are more likely to be adopted by PwD people and their caregivers if they address certain factors. These include: flexibility, creativity and adaptability (Brataas et al., 2010); providing clear ways in which they can be integrated into everyday routines; and having an obvious and distinct value for all stakeholders (Gonzalez-Palau et al., 2013; E. Karlsson et al., 2011; Rosenberg et al., 2012). These distinct values, we found, go beyond the inter- and intra- personal attitudes and practices of

PwD and their caregivers. They relate to how the care provided to PwD is embedded in a constellation of real-world necessities and limitations that the practical provision of care is continually obliged to recognize. Thus, when innovative technologies not only deliver positive experiences but also show a capacity to be embedded within, or even improve existing care activities and processes, their value is more likely to be acknowledged.

There are a number of important outcomes of our study in this regard, so, looking to the deployment of the videogame-based system we found that, for PwD themselves, the system offered the core benefits around which it was conceived, encouraging movement and improving self-reported physical fitness and encouraging the use of memory and cognitive skills. It also, as the designers would have hoped, offered a source of fun, providing PwD with a positive emotional experience and making them feel good about themselves, although certain confusions did arise about the avatars and (as is the case for most people) they were frustrated by technical breakdowns. However, PwD were themselves aware also of the social benefits the system was delivering. They appreciated the quality of the experience in the day centers where they played it as a group. The participation here itself was something they manifestly enjoyed, but it also gave them an opportunity to motivate each other through applause or encouraging comments and we noted that they made active social arrangements around the game. The downside of this, of course, was that some people disliked the pressure of having to perform in front of others and the comments could sometimes be critical rather than encouraging. On top of all this, we saw how the system provided a vehicle for enhanced intergenerational interaction. Family interactions can be strained by dementia and communication between family members can be diminished. Playing the videogames here served as an opposing force, providing grounds for interaction and enabling PwD to revivify eroded social roles and responsibilities.

In the case of informal caregivers and relatives, as a corollary of what we said above, the system gave them a shared point of interest with the people for whom they were caring. More than this, it was a way for them to have pleasurable interactions with family members with dementia in the face of other more challenging demands. In short, it was a way in which they could have fun together and there was pleasure for the caregivers themselves in seeing PwD having fun and being happy. Alongside of this, the recovery by PwD of certain social roles was of clear benefit to the family overall. A not inconsequential added boon was the opportunity for caregivers to have more time off to do their own thing, as noted previously by Schorch (Schorch et al., 2016). However, as we commented above, it is not possible for the system to simply step in and solve pre-existing family tensions. Instead, we found that, for some participants, the system became just another thing about which the family members could be in conflict

For professional caregivers in care facilities, meanwhile, the videogame-based system provided a number of concrete outcomes that could be said to contribute to the overall quality of care within their facilities. At the level of individuals, caregivers noted things like improvements in posture, improved self-awareness, and improved self-confidence. They also felt that the games were enriching the lives of the PwD by providing a source of both variety and direction. Much of this was put down to the group dynamic that had evolved with the PwD being encouraged to do exercise because there was a spirit abroad of encouraging one another in that way. The games provided the PwD with ambition, but also with a source of feedback. Furthermore, the professional caregivers had noted that the games had become an active topic of conversation in the day centers, which is itself generative. Social cohesion is at its strongest when everybody has a shared topic to talk about. At the same time, the system brought the professional caregivers certain process benefits as well. We saw above how it facilitated more flexible time management and a reduced need for supervision when everybody was playing the games.

Finally, technological artefacts, like the system presented in this article, clearly also possess the potential to generate negative experiences. We mentioned before that the technical infrastructure built around the Windows Kinect was sensitive to different environmental conditions. Depending on these conditions, the system would not always work as intended, sometimes producing malfunctions and errors. Such events did not leave participants and their caregivers unaffected. Instead, they led to frustration and a negative experience of using the system. As researchers, we were able to quickly mitigate the worst effects of these breakdowns by adjusting or fixing the system. However, in a real-world scenario such prompt support cannot be guaranteed, thus increasingly the likelihood that negative experiences will occur. While this, of course, this could be said to be the case for most technological artefacts, it has the potential to have a greater impact when designing for target groups with a lower resilience. In that case, designers in this field need to consider technical infrastructures and system setups more carefully.

Design Implications

The following implications for the design of videogames for people living with dementia have been derived from the empirical findings presented above. We are going to focus on five key concerns: 1) *Multiplayer and Collaborative aspects*; 2) *Rewards and Progression*; 3) *Individual Resources*; 4) *Feedback;* and 5) *Diverse interests and biography*. These implications may help to support designers working from a variety of perspectives, but most notably those seeking to design similar kinds of games for PwD, those who are interested in providing a broader set of possible engagements with PwD, and those who are seeking to provide engagements for other kinds of stakeholders who share some of the same characteristics.

Multiplayer and Collaborative aspects*:* The possibility of overtly competition-based and cooperative games and exercises should be integrated in order to promote social interaction between the players and maintain their long-term motivation. In the day-care centers, the researchers held the position of mediators between a number of different players at the same time. The implementation of a multi-player version, however, would enable relatives, informal and professional caregivers, or even other people such as friends (with or without dementia) to be involved in the exercises. One possibility might be that additional players are detected and integrated into the system, e.g. if they get up from a chair and do the same exercises or get into the detection zone of the Kinect camera. This proposition is based upon our observation of how groups enjoyed interacting around the games, with the games not only promoting social interaction between the players, but also creating long-term motivation to use the system. We saw this in the day-care centers, but also in the households, with various relatives such as nieces and nephews joining in. There is further scope to reflect here upon the relevance of different factors such as group composition, group size and the type of game being played, for how the games might be configured. In several study settings, for example, there were passive participants in wheel chairs who could only take part in the exercises and games in a restricted way.

Rewards and Progression: Rewards or a feedback system should be integrated. Across the results we noted there was a sense of both collaboration and competition between the participants. This cropped up in the group settings and was articulated through the surrounding banter. It was also manifest in the interaction between a grandparent and his grandchildren, who actively kept track of their performance, and Figure 7 above illustrates how one family went out of their way to maintain an active record of progress. Collaboration, motivation and the general atmosphere in the day care facilities all increased with the size of the group. Building on this, one possibility might be individual player detection and associated rewards and progression, where players are recognized by their faces or wearables. This could be simply and seamlessly integrated to reward players just during a running game or to provide them with a sense of progress across a whole training schedule. Within a framework of continuous improvement, positive feedback-mechanisms, process evaluations, and level progression, a system could be established and made open to remote intervention to continually review current needs, daily performance and overall achievements. Progress, here, should not be a static concept, but rather able to accommodate daily fluctuations or longer episodes where participants perform with below-average results. One way of achieving this would be to integrate automatic "Dynamic Difficulty Adaptation", so that the difficulty of the level adapts automatically to the current performance.

Individual Resources: Due to the degenerative course of dementia and associated variations in the daily condition, mental state and emotions of PwD, a large number of possible configurations need be provided and static programming should be avoided. Games and exercises need to be able to adapt to individual impairments and resources. This will necessitate some form of user analysis and the creation of individually-oriented activities. Individual ability to concentrate on games and exercises should be taken into account as well. Due to the different kinds of course it may follow and the divergent symptoms of dementia, it needs to be possible to determine and adjust the time frames over which exercises may be mastered. This setting, in particular, needs to be adjustable for relatives and caregivers as we noted in the results the extent to which the capacity of the players can vary on a daily basis, so an assumed starting level that is just maintained would be inappropriate. Caregivers are sensitive to these changes, as is manifest throughout the quotes provided above, so they are well-positioned to adapt the system to reflect them. In addition, we noted in the results a number of negative aspects to the current game design. Some of these would be hard to overcome because they relate to the inevitable familial tensions that arise in trying to cope with the outcomes of dementia. However, specific issues regarding how to recognise the status of an avatar and how to make the system's own operation more transparent to this community of users needs further reflection. There are clear challenges here for design that should not just be set aside.

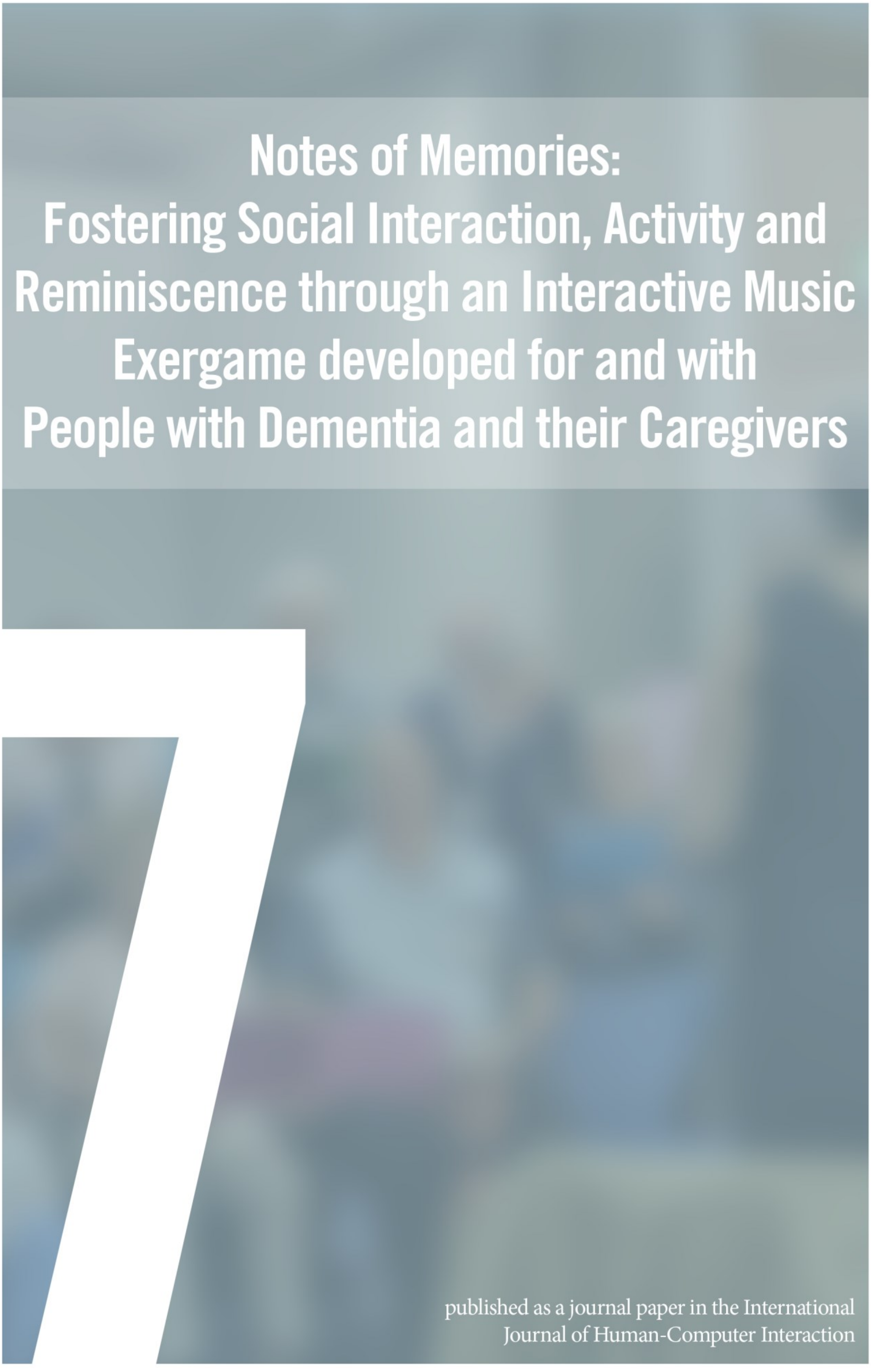
Feedback: In order to provide effective activity support, users should be given clear and immediate feedback on their status. This might include feedback on their movements, their progress in the exercise, reminders and the current score. The feedback should be adapted to the needs of PwD and their caregivers and made user-friendly and the interactions between the system and the user should be as straightforward and as simple as possible, in order to give specific users (with a wide range of cognitive and communicative capacities) the opportunity to understand what the system is trying to tell them. This, too, relates to the negative experiences we reported above, but it is also a potential vehicle for the collaborative aspects of the game as it provides a mechanism whereby current performance can be quickly gauged by everyone in the setting, adding further scope for talk and mutual support and encouragement.

Diverse interests and biography: To motivate end-users in a sustainable way, any relevant socio-biographical information that is collected should be systematically integrated into the content of the videogames. To facilitate this, an implementation option for biographical data in the form of "Procedural Content Generation", which allows developers and users to add additional content into a game and thus expand its possibilities, could be made available. The types of information that might be considered when designing virtual environments, games, and exercises could include former professions, tasks, activities, hobbies, and interests. A particular aspect of the games we noted in the results was the way in which the participants were responsive to things like music and clips from films. Giving these a grounding in personal biographies will make them even more powerful. Additionally, based on the ever-increasing IT literacy of older adults and PwD, an interface to existing technology and exercise equipment such as exerbikes, treadmills, fitness wearables, digital health and fitness applications or even entire Smart Home or AAL-systems or integration within individual IT-Systems could be considered and established. Links to existing local arrangements like sports groups or physical group activities, for instance via social media, could also serve to increase levels of individual and social collaboration and integration. This recognises the fact that the videogames are introduced into a socially-constituted world where PwD are typically already engaged in various kinds of exercise routine, so it offers a way for them to be better aligned. A further feature worth considering is personalized avatars in the form of relatives or close friends, which might provide additional visual and auditory companionship and longer-term motivation.

Conclusion

The qualitative work presented in this paper, based on a design case study with 26 participants, has shown that videogame-based systems can practically enable social interaction and collaboration in the life of people living with dementia. It has also shown that care-facilities could profit from such a system in multiple ways in terms of work relief, the provision of new experiences for their clientele and the potential for institutions to develop their own portfolio around the provision of such experiences. Professional caregivers from different institutions saw the videogame-based sessions and the sessions related to both individual and socio-collaborative activities, as having added value within their daily work routine. However, as the researchers themselves were deeply engaged in a variety of ways over the course of the reported study, it was clearly not possible to evaluate the added value of the system for professional caregivers in a real-world context, where much of what was being done by the researchers would have to be managed by the caregivers themselves. This could even be perceived to be an overhead. In that case, there is a definite need for further studies in this field that put more emphasis on the autonomous use of systems by caregivers to investigate whether the benefits do outweigh the overheads. For the PwD themselves, the level-based difficulty system and possibility of adjusting the game structure to different interests and individual physical and cognitive resources was deemed to be both effective and motivating. In particular, the diverse activities that were built in to the overall suite of games such that PwD could move from a more physically-oriented perspective to creative and biographical activities, were considered to be beneficial.

We can conclude here that - through the iterative steps of: 1) exploring individual and institutional needs; 2) long-term integration of a system and its moderation in real-world settings; and 3) including all stakeholders in the design and development process – these kinds of systems can facilitate and promote social experiences and collaborative interaction and help to maintain the independence and capabilities of PwD. At one level, the findings confirmed the value of the work for the field of assistive technologies for and with people living with dementia, in the sense that videogame-based systems can improve individual physical or cognitive resources, as observed and reported by informal and professional caregivers. However, at another level they also confirmed that such systems can facilitate and support communication and activity between and across the various stakeholders involved and therefore provide new scope for social contact, collaboration and participation. The successful integration of the system into ambulatory and day-care contexts led to a range of positive outcomes and improved the capacity of PwD to face the challenges of everyday life. Many of the participants who used the system at home took the opportunity to connect and play with relatives and grandchildren. This served to support and strengthen relationships that are otherwise often challenged by dementia. The collaborative and intergenerational synergy promoted by the system helped PwD to recover social roles that had previously been eroded and facilitated communication and interaction across different generations. These cooperative aspects also seem to have helped PwD participating in our study to regain or maintain social interactions and certain social responsibilities that were at risk of being undermined, aiding their reintegration into familial structures and their associated daily routines. At the same time, certain negative aspects of the experience of using the system bring to light some interesting further challenges for the community regarding how to progress design in this space, notably in relation to how PwD can be provided with the resources to understand the status of various facets of the system and its behavior



Notes of Memories: Fostering Social Interaction, Activity and Reminiscence through an Interactive Music Exergame developed for and with People with Dementia and their Caregivers

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NOTES OF MEMORIES: FOSTERING SOCIAL INTERACTION, ACTIVITY AND REMINISCENCE THROUGH AN INTERACTIVE MUSIC EXERGAME DEVELOPED FOR AND WITH PEOPLE WITH DEMENTIA AND THEIR CAREGIVERS

This paper presents the outcomes of an exploratory study focused on the evaluation of an interactive music exergame for People with Dementia (PwD) and their caregivers. PwD tend to isolate themselves from the outside world, therefore carers need to develop strategies to maintain communication with them. Studies indicate that music-based activities provide an effective way to achieve social interaction with PwD. At the same time, physical activity plays a major role in dementia-related interventions because it can slow down progression and provide meaningful stimulation. Our developed interactive music game bounds these two concerns together; we evaluated the system afterwards regarding its individual and social impact and its integration into the daily routines of both PwD and their caregivers, focusing on its capacity to provide both enjoyment and relief from some of the effects of dementia. Qualitative data collected over 4 months confirmed the valuable impact of music-based interventions of PwD. Of particular note was how PwD used the game to improve or maintain their physical condition while recovering past memories and an interest in social interaction.

Keywords: Dementia; music; ICT; exergame; care; videogame; social interaction; activity; memories; reminiscence; participatory design

Introduction

Dementia is primarily seen as a medical problem in our society. Most definitions (e.g. ICD-10 or DM IV) are medically- or biologically-oriented and describe dementia as a clinical condition with different symptoms (Sathyanarayana Rao et al., 2017). The World Health Organization estimates (2017) that there are more than 46.8 million people in the world with Alzheimer's or a related form of dementia (World Health Organization, n.d.). Studies indicate this number will continue to rise until 2050, by when it will affect 1 in 85 people, most of whom will live in developed countries (Brookmeyer et al., 2007). Recently, there has been move towards a less medical and more holistic view of dementia and this has begun to have an impact on public perceptions (Lazar et al., 2017a). The socio-emotional and psychological impact of dementia on the life of individuals has long been neglected. However, to have meaningful interactions with PwD, it is important to understand their experiences and social environment. A number of studies have illustrated that PwD's mental health (Patricia Heyn et al., 2004), cognitive performance (Colcombe and Kramer, 2003) and physical resources (Hauer et al., 2012) can be improved by physical training, enhancing their capacity to cope with the challenges of everyday life (Kemoun et al., 2010). Blankevoort et al. (Blankevoort et al., 2010a) found that physical activity is beneficial at all stages of dementia, with multi-faceted interventions involving endurance, strength and balance exercises resulting in notably greater improvements regarding walking speed, functional mobility and balance than exercises involving only strength training.

Creative and meaningful activities, such as art therapy or music-based activities, meanwhile, can produce benefits in sociability, improved self-esteem and manifestly positive stimulation for PwD (Hannemann, 2006; Logsdon et al., 2007; Phinney et al., 2007; Sarkamo et al., 2014). Music has particularly come to the fore as a resource for interacting with PwD of late because musical stimuli are typically processed in parts of the brain belonging to the so-called salience network (McDermott et al., 2014). This large-scale brain network, essentially responsible for the regulation and control of emotions, is left relatively untouched by dementia (Omar et al., 2011), even when it is advanced (Kiewitt, 2014). Biographically-relevant music can awaken lost memories, even when memory loss is otherwise pronounced, because of its emotional signification. Several studies have reported that music-based activities can support the treatment of dementia-based symptoms, including fear and anxiety, positively influencing individual moods and behavior (Fang et al., 2017; Wall and Duffy, 2010). Regained language skills, improved well-being, a reduction in negative emotions and an increase of self-esteem have all been observed during music-based activities with PwD (Grümme, 1998). Altogether, music can contribute significantly to the well-being of PwD, alleviate challenging situations and improve the quality of life for both PwD and their caregivers.

Information and communication technology (ICT), in particular exergames (video games with physical activity), have gained relevance too, lately, with studies showing that they can lead to improvements in fitness, adherence and balance, regardless of age (Larsen et al., 2013). Exergames that combine physical, cognitive and socio-emotional objectives have the potential to further support PwD by promoting social interaction and collaborative activity, serving to alleviate the depression, anxiety and stress commonly associated with dementia. While studies of music-based activities indicate that they have individual and group-based benefits for PwD and their care-network, little research has examined the role of technology, music and music-related activities in their everyday lives over extended periods (Fang et al., 2017). This is accompanied by a lack of technology, especially (exer)games, focused upon music for PwD and their caregivers. Thus, there is a strong need for more studies investigating how music-based activities might be combined with other physical and cognitive activities such as dance, physical exercise and video games (Fang et al., 2017). This itself implicates empirical and design-oriented studies that can uncover and support the needs and expectations of PwD and their caregivers through close examination of the individual and social impacts of technological interventions over longer periods of time (Meiland et al., 2017). This underscores the need for more focused studies in HCI that can inform the ongoing development of ICT-based systems such as music-based exergames for PwD and their caregivers.

In this paper, we report on the results of a 4-month study that focused on the evaluation of a music-based exergame for and with PwD, their caregivers and additional stakeholders. The specific goal of the study was to investigate how music-based exergames might affect the quality of their lives. To this end, we accompanied 20 PwD and their caregivers in real-world environments (households and day-care), conducted a total of 24 semi-structured interviews and observed their interactions with the game over a period of 4 months. On the basis of our results, we illustrate that our music-based exergame created opportunities to foster memories, initiate social interaction and increase physical activity for PwD and their caregivers. Over the course of the evaluation, we observed that the system had positive psychological, social and physical effects in both day-care and household settings. As a consequence, our study provides a new body of insights for this currently rather under-developed domain. Researchers and developers in the field of Human-Computer-Interaction and beyond may then benefit from our results and reflections, with the ultimate goal of improving the design of appropriate technologies for PwD and their caregivers.

RELATED WORK

Designing technologies for and with PwD in their social milieu requires that researchers and designers explore and understand how dementia affects the lives of those involved. In this section, we examine previous work regarding dementia and the challenges it poses in daily life. We also examine the value and effects of music, singing and dancing in relation to dementia and the current state-of-the-art regarding music-related technologies and the design of technology for PwD.

Dementia in daily life

Demographic and social changes, such as increasing life expectancy and consistently low birth rates, have led to an increase in the number of older adults and, consequently, a rise in the number of cases of dementia (World Health Organization, 2017). In view of anticipated increases in the number of PwD, dementia has come to be regarded by some as “the most significant epidemiological challenge of the early 21st century” (Kitwood, 2013). Dementia not only results in physical limitations, but also affects the social life of PwD, as well as their relationship with their family members (Brodaty and Donkin, 2009; Coon and Evans, 2009; Schulz and Sherwood, 2008). The impact of dementia on social and individual family life can be enormous (de Vugt and Dröes, 2017), with PwD’s behavioral changes posing a serious organizational and emotional challenge. Family members often need to re-organize daily responsibilities such as taking care of the household, financial and administrative tasks and correspondence, as well as decision-making. Often, family members have to put their own needs and emotions aside in order to take care of their loved ones, resulting in emotional and physical exhaustion. Caregivers often need to reduce their social contact to meet the temporal demands of providing care (Sörensen and Conwell, 2011; Sütterlin et al., 2011). Behavioral changes in PwD can thus confront relatives with organizational and emotional challenges they are not necessarily equal to (Schorch et al., 2016). Research regarding the physical, psychological and social effects of dementia has therefore become an increasing focus of scientific interest. The medical aspects have been studied for some time but, lately, the social aspects of dementia have started to receive more attention because the symptoms can limit PwD in their everyday life. Different measures can be taken to slow down and limit the loss of cognitive and physical abilities of PwD. Many medical and non-medical treatments aim to maintain practical skills for as long as possible. This can help PwD and their families to cope with Activities of Daily Living (ADL) (Chalfont et al., 2018). Although there has been a paradigm shift regarding PwD and their well-being, established negative and deterministic views of dementia still persist (Kitwood, 2013). The decline in cognitive abilities can include diminishing memory, reduced judgement and abstraction, impaired concentration and attention, temporal and spatial disorientation, loss of the ability to perform everyday actions and recognize functions (e.g. of objects), progressive linguistic impairment, and reduction of the ability to develop concepts and recognize concepts used by others (Kitwood, 2013). However, social factors such as culture, locality, social class, level of education, financial resources and the availability of support and services can also affect the course of dementia (Kitwood, 2013). In terms of **physical impact**, the cognitive loss and non-cognitive symptoms can reduce PwD's ability to perform everyday activities, resulting in a diminished quality of life and loss of autonomy. This often makes PwD dependent upon their social network and the support of an individual carer.Due to the fact that PwD's are not a homogeneous group, coming from different family and/or institutional situations and with different needs at different stages, the need for a person-centered approach is of utmost importance (Alheit et al., 2015; Kitwood, 2013). Therefore, adequate responses, communication and interaction with PwD are essential to maintain the coherence of their social environment. Kitwood's Person Centered Care Approach (Kitwood, 2013) focuses upon a PwD's humanity, arguing that they should be seen as a person with needs, just like anyone else, rather than judging them on superficial appearances. This perspective seeks to recognize that dementia not only restricts individual physical resources, it affects the **social life** of PwD and their relationship with family members and others around them. It also recognizes that the **emotional and social impact** of dementia can include a loss of primary bonds, a need for comfort, for identity, for activities and for integration, united in a need for love and emotional security (Kitwood, 2013).

Music-based interventions

There is a vast repertoire of non-medicinal approaches to interacting with PwD, coming from a variety of theoretical backgrounds, with music being one such approach that has become increasingly established. In relation to this, Phinney et al. [2007] highlight the importance of meaningful activities that largely depend on involvement, pleasure and enjoyment, thereby providing PwD with a sense of connection and belonging and maintaining their sense of autonomy and personal identity (Phinney et al., 2007). Music accompanies people through different stages of their lives and transcends verbal communication, often working most forcefully at an emotional level (Wall and Duffy, 2010). The uses to which music might be put are almost as diverse as the biographies of the PwD themselves. When examining the potential of music therapy to aid cognition in the context of Alzheimer's, Fang et al. [2017] investigated the literature for different techniques, clinical trials, and possible mechanisms. They found that music-based activities can reduce cognitive decline, especially with regard to autobiographical and episodic memories, psychomotor speed, executive functions and global cognition. They thus recommended the earliest possible use of music therapy as an intervention for dementia (Fang et al., 2017).

As the auditory/acoustic system is only minimally affected by neuronal changes, music offers an especially effective way of gaining access to PwD, even when at advanced stage, with verbal communication all but impossible and their reactions almost non-existent (Brotons and Koger, n.d.). Hanser et al. describes the reaction of PwD to music as an "awakening", a means of finding their way back to themselves (Hanser et al., 2011; Whitcomb, 1994). Even in the early 90s it was known that "music creates an access to the healthy parts of the person with dementia", sometimes leading to short-term reversion of its progress (Grümme, 1998). Music can underpin emotional approaches that some consider "the primary and most important" route to "open[ing] up more channels of experience" (Kiewitt, 2014). It can also support contact as a "transcendental language" (Alheit et al., 2015) by evoking personal memories, when this is no longer possible through words. Its use strengthens identity and self-confidence, communication processes are reinvigorated and isolation counteracted. The selected musical material must, of course, correspond with the biography of the person concerned. Music is often associated with emotional life events and experiences and can facilitate the later recollection of such memories (Kiewitt, 2014). Practically-speaking, music activities may require active participation, e.g. singing songs, dancing or moving and the fixed or improvisational use of instruments, or receptive participation, where the recipient simply listens (Benveniste et al., 2012).

Looking at these approaches in more detail, **singing songs** builds "the methodical center in music-based activities with PwD" (Muthesius, 2010). Throughout their lives people acquire a repertoire of familiar songs and melodies (Aldridge, 2003). Accessing this is often still possible, regardless of the stage of dementia (Grümme, 1998). Through singing, the well-being of PwD can be improved by participating in social activities such as choirs, thereby retaining involvement in activities that fulfil the desire of many PwD to “function” as usual (Aldridge, 2003). By showing PwD how to use remaining competencies and maybe develop new skills, an increase in their self-esteem can be achieved (Benveniste et al., 2012). **Dancing or moving to music** with others positively influences self-image and strengthens a sense of togetherness and improves social skills (Guzmán-García et al., 2013). It can also counteract a decline in physical mobility (Grümme, 1998). **Listening to music** can have therapeutic effects, often by focusing on known or popular pieces, improving relaxation, evoking reminiscences, activating positive emotions, supporting acceptance and grief, stimulating emotional expression and influencing mood. Applied in groups, receptive music activities facilitate contact and communication, further improving self-esteem and autonomy (Aldridge, 2003).

There are many potential uses of music when interacting with PwD. It can support an individual’s physical, emotional, mental, social and cognitive needs by restoring, maintaining and promoting mental, physical and emotional well-being. As a transcendental language, musical activity represents a way of potentially accessing PwD, even at an advanced stage. It can strengthen a sense of identity and self-confidence, stimulate communication processes and counteract isolation. For our own work, these prior studies provided an important background when selecting appropriate study sites, deciding the degree of active participation required, choosing musical material and assessing the degree of engagement and collaboration with PwD, their families, and caregivers required.

Human Computer Interaction, Music-based Technology and Exergames in Dementia

Recently, developers and researchers in the field of HCI have taken a particular interest in designing together with children and younger adults (Aal et al., 2015, 2016; Mazzone et al., 2008; Rode et al., 2015; Weibert et al., 2016), older adults (Davidson and Jensen, 2013; Ogonowski et al., 2016a) and also with people with dementia (Hendriks et al., 2014; Lindsay et al., 2012b; Slegers et al., 2014; Unbehaun et al., 2018c, 2018d, 2019). ICT is now widely used for health promotion, prevention and healthcare support across all social groups, including older adults (Marston and Samuels, 2019; Martínez-Alcalá et al., 2016). Often, it seeks to support certain aspects of the lives of older adults, such as social participation, personal autonomy and their quality of life (Müller et al., 2015; Pinto-Bruno et al., 2017b). With regard to PwD, assistive technologies, telecare, security and monitoring are amongst the most accessible low-level technologies available on the market. Beyond this, a number of technologies have been specifically designed to support the daily activities of PwD and their families (Martínez-Alcalá et al., 2016).

Music-based Technology for Dementia

The HCI-based literature regarding music is very broad and much of it is simply beyond the remit of this paper. A body of work that is somewhat closer to our own interests looks at the relationship between music and fitness-based activities (Biehl et al., 2006; Hartnett et al., 2006) and rehabilitation (Music and Murray-Smith, 2010). The most pertinent music-related literature in HCI, however, directly focuses on how music might contribute to therapy for PwD. This literature generally recognizes the potential benefits of using music with PwD. Several studies suggest that both passive music consumption and more active participation in singing and dancing already play a role in the lives of PwD in care homes (Morrissey and McCarthy, 2015). Thus, some studies focus on providing smartphone-based applications to identify the music preferences of PwD and deliver filter-based recommendations based on this information (Stoeckle and Freund, 2016). Others recognize the difficulty PwD may have with conventional interfaces and offer distinctive interfaces to more effectively handle the playback of music (Seymour et al., 2017). In a more active vein, some research has developed interfaces that might enable PwD to engage in creative music-making and musical performance. Riley [2007], for instance, presents a creative use of touchscreens and Favilla and Pedell [2013] extend this to touchscreen-based collaborative music-making for PwD (Favilla and Pedell, 2013; Riley, 2007). Morrissey et al. [2016], drawing upon McCarthy and Wright’s [2015] arguments about participation in experience-centered design, suggest using technology to support active music sessions in care homes with physical percussion instruments and props (Morrissey et al., 2016b). Some research notes that music therapists are becoming a scarce resource as the number of PwD grows and has suggested ways that technology might support the remote provision of music therapy (Kosugi et al., 2013). Of particular note is an interactive music game constructed by Tsiakis et al. [2016] that was specifically designed to ‘improve the attention levels’ of PwD (Tsiakas et al., 2016). Here, a robot plays PwD four songs and asks them to name them. It assesses the performance of the players and modulates the level of difficulty accordingly. At present this game is only at the design phase and has not been implemented. It was also founded solely upon the music therapy literature rather than being grounded in specific studies with PwD. Our own work differs from the above literature in three key respects: 1) it binds together studies of PwD, the design of a music-based system, its implementation and evaluation of its use; 2) it involved the full gamut of stakeholders, including PwD and their caregivers, in the design process; and 3) it brings together an interest in using music for both cognitive and physical enhancement.

The Use of Serious Games with PwD

In our study, we used a music-based exergame directed towards encouraging active participation in musical experiences. Videogames primarily designed for training rather than pleasure are called "Serious Games". This includes exergames, which involve movement exercises (Ben-Sadoun et al., 2016). Several studies focus on the positive cognitive effects of Serious Games, including enhancement of attention and memory in PwD (see McCallum and Bolites [2013] for an overview). However, no studies focus on using physical and 'serious' exergames along with music as an intervention in dementia – though Music & Murray-Smith [2010] looked at this more broadly in terms of rehabilitation. Most studies involving exergames relate to rehabilitation after strokes or heart disease. An example of using serious videogames in the daily life of older adults can be found in the work of Vaziri et al. [2016, 2017]. Here, older adults trained in front of their television at home to reduce their risk of falling. The system offered exercise sessions that incorporated a fall risk assessment with discrete measuring technologies and adaptive assistance functions (Vaziri et al., 2016a, 2017b).

Less research has studied exergaming in relation to cognitive impairment. Padala et al. [2012] found that exergaming can have a positive effect on the balance and gait of people with Alzheimer's (Padala et al., 2012b). Exergames and cognitive Serious Games can also positively influence people at a social and emotional level, reducing depression and stimulating interaction. Yamaguchi et al. [2011] examined the effects of video-sports games in a fixed care setting (Yamaguchi et al., 2011b) and found improvements in emotional and social health in situations of cognitive impairment, indicating the value of further research in this area. Robert et al. [2014] have therefore argued that Serious Games could be useful instruments for interaction between professional nurses and patients with cognitive limitations and have strongly advocated intensified collaboration between the relevant disciplines (Robert et al., 2014b).

One of the few studies that has specifically combined video games and music-based therapy was conducted by Benveniste et al. (2012). PwD used Wiimotes to improvise music or play predefined songs on a virtual keyboard, with an emphasis on reminiscence. By finding themselves “capable” of making music, participants increased their self-esteem and displayed improved competence at an emotional and social level. Benveniste et al. (*op. cit.*) concluded that most users with mild to moderate dementia would be able to understand and use the interface. There was also notable enthusiasm for the system from caregivers. Importantly, the authors stressed that musical exergames for PwD should be as easy as possible to play so that success is readily achieved. Success, in this case, is not only mastering the game, but also finding pleasure in creating music. In Benveniste et al.’s study, the participants were actively making music to power reminiscence. In our system, active music-making would be hard to combine with walking exercises, without a risk of falling. Walking, however, constitutes a performative element that is combined with listening, so it has both active and receptive features. Of course, the game did not constitute formal therapy. It was a “music-based intervention”. Nonetheless, it had positive outcomes for both self-esteem and identity, as well as motor and cognitive abilities. The key distinction between our own approach and Benveniste et al.’s, however, is the extent to which our system became a vehicle for interaction between PwD and their caregivers. We will be focusing on this powerful social outcome in the latter part of the article.

Research Focus and Contribution

Inspection of the above literature reveals that there is currently a lack of studies that combine video games and music-based activities while examining the effects for PwD in the context of their social milieu, despite broad recognition of the value of music-based interventions, serious games and exercise for PwD**.** Some studies suggest that music and movement considerably foster the individual health and well-being of PwD. Thus, music and movement in exergames may provide meaningful activities and improve their physical and mental activity. However, it seems that, to date, there has been no specific investigation of the factors influencing the user experience of music-based exergame systems for PwD.

Hence, in this study we will focus on the evaluation of a music-based exergame that has been designed for PwD and their caregivers (see Methods). During the process, the PwD, their relatives and caregivers were involved in providing their ideas and feedback regarding the system. Over the course of the paper, we will investigate the user experience, focusing in particular upon how the system promoted active enjoyment in use and emotional interaction. We will examine how the music-based exergame affected PwD and their caregivers in an individual and social manner. Thus, our results may help future designers to understand better where to put more emphasis when designing exergames for specific target groups. In the discussion we provide a number of important insights that became manifest through our analysis of the results.

Project Background and Prior Work

The work presented here formed part of an interdisciplinary research project (Nov 2015 - Dec 2018) involving different research partners from various domains, including sport and nursing science, care-software engineering, game development, and institutions involved in the care of older adults. The overall aim of the 3-year project was to improve the physical and mental activity of PwD and provide sources of relief for their care-network. A basic prototype was already available at the start of the overall research project (in Nov 2015) that had been developed for a previous project (2011-2014), aimed at improving and assisting older adults in general with a risk of falling (Gschwind et al., 2015; Ogonowski et al., 2016a; Vaziri et al., 2017b). The technical infrastructure and the games were still applicable because the majority of the games focused on strength and balance, which are important factors for fall prevention but also for PwD. This prototype had been refined over the course of the prior project and was now adapted to the new target group, drawing upon the ongoing observations, evaluation and user feedback. Some prior exergames and training concepts (especially the strength games and reaction assessments) were preserved and converted into a new game engine (Unity), changed for the new target group and simplified, while other games were no longer included in the system because they required too high a level of physical and cognitive skill.

Due to the exploratory character of the overall project, right from its beginning (Nov 2015 – Apr 2016) we sought to gather insights regarding the daily life and routines of PwD and existing practices, organizational and social perspectives, individual and social needs and challenges confronting PwD and caregivers in their everyday social surroundings. We therefore conducted interviews and observations of daily activities in different day-care facilities and private households. Subsequently, we explored the impact of the available basic prototype in different day-care centres and households over 8-months (until Dec 2016). The first general results regarding the exploratory study had already been published before the music game was developed and evaluated (Unbehaun et al., 2018a, 2018c, 2018g). These studies concentrated in particular on evaluating and understanding the interaction behaviour of PwD and the impact of the basic exergames that focused on the training of physical activity, cognitive abilities and well-being of the PwD and their caregivers. They did not have an explicitly creative focus. Nor did they explore the specific social outcomes, such as the power of reminiscing, that feature strongly in this study.

However, the involved relatives and caregivers had emphasized that they considered a creative perspective to be especially important. Drawing upon insights and recommendations from practitioners, therapists and experts around the topic of activation in dementia, we therefore decided to add a creative component to the whole system. Overall we developed 4 games in the creative section of the system: 2 quiz games; 1 movie theatre; and 1 music-based exergame. Caregivers and experts put particular emphasis upon incorporating music-based activities in the system because it was already used on a regular basis in care-institutions and had become increasingly established, with promising effects, in therapy. One outcome of an interview study with professional caregivers (see Methods, Phase 1 & 2; Jan 2017 – Apr 2017) was that they actively noted the potential of music by saying that: "*We sing a lot with our guests, it is often accompanied with the piano or guitar.*" Another professional caregiver said,*"it would have been my wish for you to do something with music."* Professional caregivers and therapists experienced in working with old people for many years, told us*: "Music is a great tool as well as a key. Where speech stops, we can start with music."* Having stressed the potential of music, caregivers and professionals also suggested implementing elements that would animate PwD and encourage them to sing, dance or simply move to the music. Our growing familiarity with the settings and the common social and institutional practices we observed in them, together with our discussions with various different experts and caregivers, gave us the idea of constructing an interactive music game that combined movement and music.

In this paper, we focus on the evaluation and outcomes of the music-based exergame, which was designed to support the daily life of PwD and their relatives at both an individual and a social level. We therefore present and discuss the results from our evaluation of this game and focus on the individual and social impacts of its use of music and movement. This work formed one specific strand of the overall project and it pursued its own trajectory and delivered its own unique findings that may help future designers to understand better where to put more emphasis when designing music-oriented exergames in dementia.

Prototype: System Overview

The following sections describe the main system and the different aspects of the music-based exergame.

The General System

The system ran on a mini-computer (Figure 17, 1) that was connected to a TV (Figure 17, 2) to provide an easy and familiar point of access. The system could be operated using a Buzz Controller with colored buttons (Figure 17, 3) and was connected to an MS Kinect (Figure 17, 4) that detected the participants' movements when interacting with the system. A male and female 3-D model and underlying biomechanical model were provided for the Kinect-based motion detection (Figure 17, 5). The system had two modes: 'free play' and 'training'. In 'free play' mode, the participants could select and play one of the different exergames, then choose a new game.

Figure 16: Technical Infrastructure

The menu interface was specifically designed for the target group to keep it simple (Figure 18). The training mode created an individual training plan for the participant, who could play several compatible exergames to complete a training session. The training plan was designed to be followed over the next few weeks, but was modified automatically, based upon the participant's ongoing results.

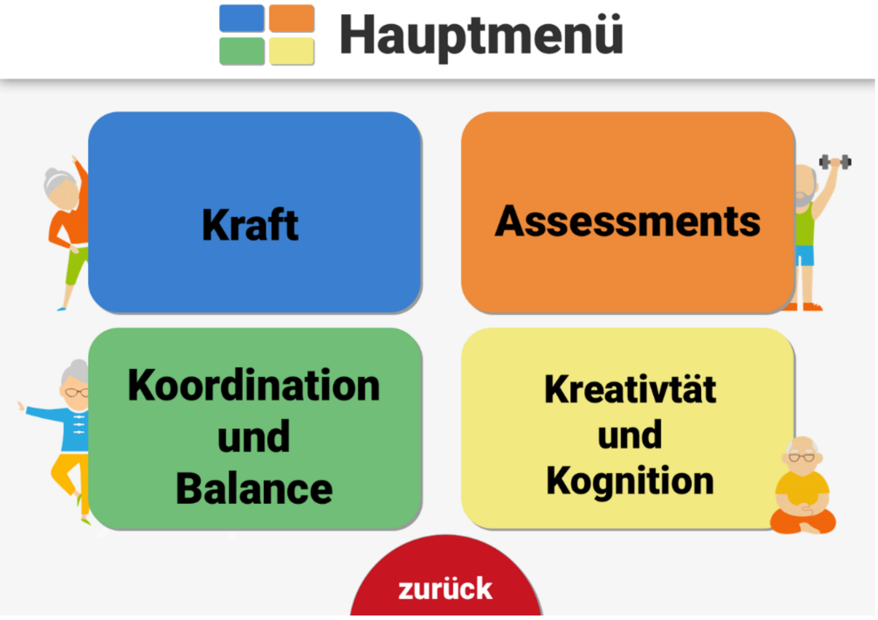


Figure 17: Main interface

The Music Room

Overall, the games shown in the main menu (Figure 18), were divided into 4 categories. The physical training was divided into strength exercises and different assessments (such as reaction tests or balance). The strength exercises focused on movements that are important during functional movements, walking, and recovering balance. The four balance and coordination games focused on providing percipience, balance, reaction and aimed to present tasks in a playful fashion. The creativity and cognition category covered a variety of games that combined movement, creativity and cognitive tasks. This game category includes two quiz games, a movie theatre and the music-based exergame, which was developed in cooperation with a company that provides songs especially for older adults. All of the songs were from the 1930s to 1960s and were partly sung by a well-known older musician. 160 different folk, traditional and evergreen songs were selected overall in negotiation with the project partners and the music company. The user interface needed to be arranged such that the game process would be easy to understand without needing a special tutorial (Figure 18 & Figure 19). Using the Buzz controller and the provided color scheme, the user could navigate between the different kinds of music (Figure 19 blue-left arrow/orange-right arrow) and confirm his selection with the yellow button (Figure 19).

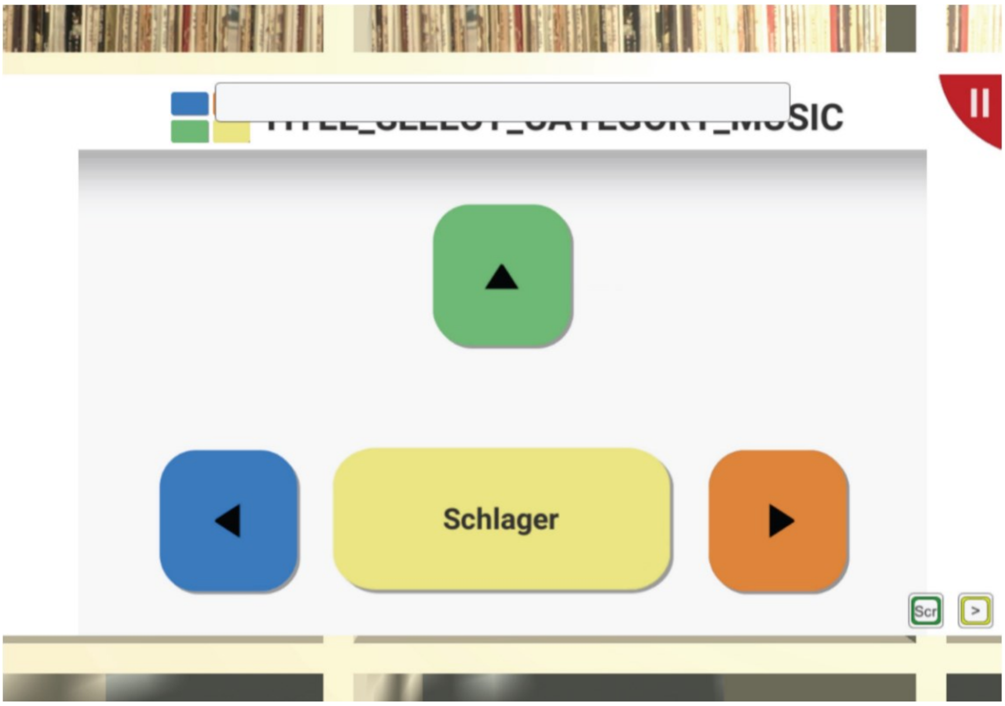


Figure 18: Menu to select the music (in German “Schlager” translates to “folk music”)

The music-based exergame focused on playfully strengthening and improving endurance in the lower extremities by walking in a virtual setting on a spinning vinyl disc (Figure 20). To promote physical activity, the PwD had to keep stepping in front of the system to make the music continue. If the participant slowed down, the music also became slower and quieter. If they stopped walking, the song started to fade. However, we found that simply listening to the songs brought the participants pleasure, so we incorporated an option where the virtual music room could be used without needing to walk, though the song had to have been unlocked by previously finishing a game. Here, they could just watch the performer singing their chosen song.

Figure 19: Virtual Music Room

Virtual Game Environment

Feedback from caregivers and PwD regarding a mock-up of the system (see methods Phase 1&2) suggested that the environment needed to be a familiar to put the PwD at their ease. A key aspect was therefore that the music room should look like a living room. This was realized in a way that closely resembled the original mock-up, with a carpet in the background and an old-fashioned and easily recognizable record player with vinyl records in the foreground (Figure 4). The presentation of the prototype was based on guidelines suggested by Mayer & Zachs (Mayer and Zach, 2013b), i.e.: 1): A well-known and familiar object the participants might once have used for reference; 2) A simple and clear concept to avoid overtaxing or distracting the PwD; 3) Facilitating regular individual feedback and encouragement from researchers or other stakeholders; 4) Making the instructions and controls as easy to learn as possible and maintaining their consistency; 5) Enabling support in a familiar social environment by explaining the system to relatives in the households so that they could train with the PwD if they wished to; 6) Maintaining visibility and avoiding visual distraction by keeping the design very simple and with the same colors shared between the screen and the buzzer, even if the functions of the different buttons might differ for each game. By following these guidelines we adjusted the music room by: 1) using objects familiar to the participants such as the record player and the vinyl and the music itself, which it was anticipated all of the participants would know; 2) providing a clear concept, where the user only had to walk while the music played (with the music fading out if the user stopped walking); 3) ensuring that playing the game was only done in group settings or with a relative or caregiver, so that feedback and motivation could be provided while walking; 5) using the Buzz controller with the big and colorful buttons and keeping the controls consistent so that the user could easily memorize the functions; 6) insisting that, in all of the households, the system be used in close cooperation with the relatives who could play along or be nearby and offer support if challenges occurred; and 7) making sure that the game didn’t have any distractions in the background or necessitate any additional activities apart from the main task of walking.

Methods

The study draws upon research in both day-care facilities and domestic environments. It was conducted between January and August 2017 and involved PwD and their caregivers. The PwD in our study were diagnosed with early to moderate dementia. The study was formulated as a design case study, more or less as originally articulated by Wulf et al. (Wulf et al., 2011). In principle, the approach consisted of three phases: (1) a pre-study that involved empirical analysis of existing individual and social practices in the specific field; (2) design of innovative ICT-based artefacts related to the findings from the pre-study; and (3) investigation of the interaction with and appropriation of the designed technical artefact over a longer period of time. The focus in this paper is upon the final phase, so we will only briefly summarize the first two phases before focusing upon the implementation of the system and its outcomes in the findings section.

Phase (1&2): Initial Interviews, Ideation Workshops & Design Challenges (4-months pre-study)

In a **first** iterative step, we began with an empirical study regarding existing practices, organizational and social perspectives, individual and social needs and the challenges confronting PwD in their social environment, to get insights into the role of music in their daily life and routines. We sought meaningful data regarding the participants’ and other stakeholders’ daily routines, their biographical background, memories, the social environment, their experience of using technology and their current attitudes and practices. We, therefore, conducted a total of 12 semi-structured interviews and observed the PwD’s daily activities in different day-care facilities and private households. We conducted the interviews with 5 PwD, 2 relatives and 2 professional caregivers and three experts (a practitioner; a music therapist; and a member of the regional Alzheimer Society). This approach allowed us to get a differentiated and reflective insight into different perspectives, interests and expectations.

In a **second** iterative step, we created design challenges to briefly outline the results of the interviews that might inform the design. The design challenges were largely organized according to the following music and movement-based requirements: 1) The game should use music to engage PwD by enabling them to play their favourite songs while interacting with the system; 2) The game should be easy to access and intuitive to play; 3) The game should recognise that the physical and cognitive resources of PwD are often very limited and their concentration when playing games may fade quickly; 4) Relatedly, the game should recognise that PwD have limited physical capabilities and may need to pause. To cover the latter points, the game needed to provide time out for sitting down and regaining strength, as well as focusing on simple movement sequences that would not overstretch PwD and ensure their safety. A fifth design challenge was that the exercise and training should not only target improvements in physical activity and cognitive resources but also maintain or stimulate social contact, interaction and collaboration to support PwD's everyday activities. This aimed to recognize that music had always played, and continued to play an important role in the daily life of PwD. This led to the idea of a virtual music room, which we illustrated in the form of a paper-based mock-up that would address the stakeholder needs and expectations uncovered during the first workshops and interviews. The involvement of a record player with vinyl records, which most of the participants had encountered or even used, helped them to recognize the room as a music room (Figure 21).

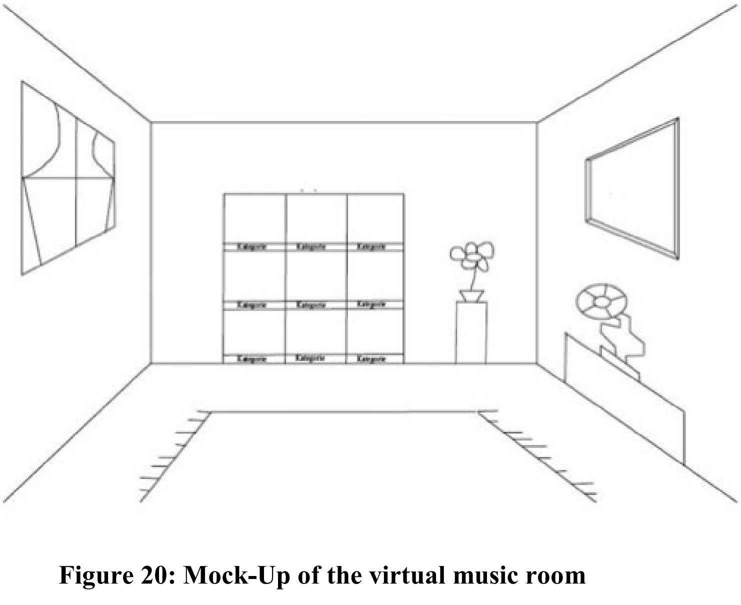


Figure 20: Mock-Up of the virtual music room

In a **third** iterative step we conducted several ideation workshops together with PwD and their carers. Within these workshops we discussed possible scenarios, use cases, technical restrictions and barriers. In this step, the PwD and caregivers were involved as co-designers and we drew upon their different bodies of knowledge, interests and aspirations as the system evolved. Based on the results, we then explained what elements would be needed to develop the game. This brought about a focus on specific aspects such as the graphical arrangement of objects, the music portfolio, levels, speed, required movements, degrees of difficulty and user interface. In a third set of workshops, the nature of the virtual environment and general functionality became the focus. As a range of movements, including dancing and sport activities, but also more gentle movements, were associated with music by PwD and their carers, walking was identified as the main activity in the game itself. Walking on the spot and on a virtual record player was considered a safe, technically feasible and particularly motivational and unobtrusive idea by positioning the player on a recognizable device in the middle of the room.

Phase 3: Deployment - Research Settings and Participants

We evaluated the game over a period of 4 months. To get a broad picture and diverse impressions, we deployed the system in a set of different households and a day-care facility. As we were working in different settings, we needed to collaborate very closely with the care-institutions and the participants, going to the day-care facility twice a week, conducting training sessions and visiting participants in their homes on a regular basis, typically once or twice a week. In both settings, there was regular weekly supervision and moderation to help if technical problems occurred, with participants being supported and motivated or simply played with, so as to observe and make sense of their reactions. In the day-care setting, the system was permanently installed for 4 months. Twice a week, two researchers visited the center to moderate the sessions and help if needed. There was a division of labor between the researchers, with one moderating the session and the other taking notes, so that one person was always available and could help the PwD without distraction. The system was installed in a specific room in the facility, where the training took place without the help of carers or nurses. There were also fixed installations in the households. Here, in contrast to the day-care center, both the PwD and their relatives were asked to familiarize themselves with the game and train on a regular basis. In most households the PwD and their relatives had no problem operating the system themselves and developed their own training schedule.

The evaluation included 10 older adults with diagnosed early to moderate dementia, aged between 70 and 90 years. There were eight women and two men, either with the system at home or playing it regularly in the day-care center. Seven of the participants went to the day-care facility and most attended the various sessions on a regular basis. The number of participants in a session varied, because not every participant was in the care-facility every day. It also depended on the health and mood of the participants, who did not always want to play. Outside of the sessions, the training room was left open and every guest in the facility could come in and play. Over time, a fixed set of six to seven people became regular participants in the sessions. 3 professional caregivers and 3 relatives, one volunteer, 2 physiotherapists, and one music therapists also participated in the study. The two physiotherapists worked for the care and medical service provider, which was also a partner in the project. They visited the domestic participants on a weekly basis and played the games with them, focusing on their physical movements. The volunteer, who mediated for the local provider of social and care services, helped to support the relatives in various households caring for PwD on a weekly basis. In the case of Ms. L.'s household, they did the shopping together twice a week and played games. She also helped with organizational and administrative matters. The music therapist visited the moderated group sessions in the day-care sessions, focusing on the impact of the musical aspects of the exergame.

Ethical approval for the study was given by the ethics board of University of Siegen. All participants needed to have access to at least a TV with an HDMI port at their home or to be going to the day-care center. With the PwD participating at home, there needed to be at least three meters space in front of the TV, so that they could use the system without risk of injury. No financial compensation was offered to the participants. Table 4 gives details of the study sample. For both health and personal reasons, the number of participants declined over time. Mrs. A. for example, did not participate for over eight weeks because health issues took her out of day-care. When she came back she was very frail, did not recognize the research team and could only move with a walker. Luckily, she recovered quickly and was able to participate again before the project concluded. Mrs. U. and Mrs. L. left day-care shortly before the end of the study and did not participate in the final interviews. Mrs. S. did not participate during the latter half of the study because her dementia had progressed too far, though she continued to come to the sessions.

ID	Participants	Age	Dropout
1	Mrs. M.	85	
2	Mrs. L.	90	
3	Mrs. G.	79	
4	Mrs. L.	86	no participation in final interviews
5	Mrs. A.	84	took an eight-week break (health issues)
6	Mr. P.	90	
7	Mr. H.	88	
8	Mrs. U.	76	no participation in final interviews
9	Mrs. T.	72	
10	Mrs. S.	83	no participation during the latter half of the study (progression of dementia)

Table 4: Study Participants

ID	Stakeholders	Setting
11	Music Therapist	Day-care and ambulatory care
12	Professional Caregiver	Day-care
13	Professional Caregiver	Day-care
14	Manager and prof. Caregiver	Day-care
15	Mrs. L's Granddaughter	Ambulatory care
16	Mrs. M's Husband	Ambulatory care
17	Mrs. M's Daughter	Ambulatory care
18	Volunteer	Ambulatory care
19	Physiotherapist	Ambulatory care
20	Physiotherapist	Ambulatory care

Table 5: Study Sample Stakeholders

Phase (4): Evaluation & Data Collection (4-months)

After developing the final prototype, we visited both settings and introduced the system to the participants, including its components and functionality. Then, we undertook an initial set-up and played a trial game together. The participants were also given a manual explaining the main system and its functions. In the households this introduction was repeated several times to ensure they knew how to operate the menu, start the games and finish them. As noted above, the households were visited once a week throughout the evaluation and given support if problems arose and the day-care center was visited twice a week over the same period. At the end of the evaluation period, we conducted 12 semi-structured interviews overall, with a sample of 3 PwD and 2 of their professional caregivers, 3 relatives, the volunteer, the manager of the day-care center, and 2 physiotherapists. To do this, guidelines for the semi-structured interviews were created. The creation of these guidelines allowed for comparability between the interviews. The interviews lasted an average of 60 minutes. With regard to data collection, the decision was made to use semi-structured rather than structured interviews, so that the participants were allowed some measure of freedom in their responses. At the beginning of the interviews, the kind of data being gathered was explained together with how it would be protected, before asking for permission to start the interview. The interviewees were told that their data will be treated completely anonymously and could not be traced back to them. The first part of the interview focused on their perception of the exergame and experience of interacting with it. We started the interviews with questions regarding their usage behavior (game usage, music preferences, adherence), then followed with a discussion of how the system was started and played (single player or with others). We then asked about their positive and negative experiences with the game. In the second part of the interview we focused on changes and the impact of the system. We were interested in the reactions of both the participants and the stakeholders (relatives, caregivers and external parties) regarding the music and songs as well as the physical challenges. We also sought to investigate how the music affected the individual mood and well-being of the participants and how the social dynamics changed because of the music. We were curious as to how the game mechanics fostered different levels of activity and stimulated communication between participants and relatives/caregivers. In addition, we wanted to get some sense of how continuous use might have increased the general motor abilities of the participants.

The data was supplemented by research notes that captured direct observation of the participants' interactions with the system and reports of their experiences of using the system across both settings. Overall, we amassed field notes relating to 67 sessions (31 in the households and 36 in the day-care center) and also kept a record of our exchanges with the participants via email and telephone. The field notes were gathered by two researchers with two different assigned roles. One of these roles was to lead and moderate the workshops, including setting up and starting the technology as well as supervising and motivating the attending participant(s). The other researcher just observed the interaction of the participants during the sessions, documenting the collaborative aspects and social experiences of the PwD and their caregivers while using the system, and noting whether these were positively or negatively perceived. To ensure continuity, we talked to the relevant actors about the same topics at different times and in different levels of detail. We also talked to other stakeholders about the same topics and discussed the findings more broadly within the project team.

Data Analysis

The qualitative data consisted of audio recordings of interviews and field notes collected during the interviews and observations. Data analysis was performed using a top-down Thematic Analysis (TA) approach (Braun and Clarke, 2006) to focus on a detailed analysis of the existing data, following a series of established steps, including first, coding of the material, then a systematic revision of the coded segments, and identification of code families and, lastly, their relationships in the search for themes (Braun and Clarke, 2006; Gibson et al., 2015). The transcribed interviews were reviewed and coded by trained research assistants. We created and named the following themes: *Socio-Emotional Behavior; Interaction Effects and Reactions; Social Aspects; and Physical Effects*. These were derived from our original codes in the TA process, which included generating initial codes like motivation, facilitating memories, audience participation, engagement, movement, etc. An overview of the codes can be found in Table 3. Coding differences were discussed and eliminated by adding codes, editing them or deleting them. We identified a number of empirical codes that were used to encode relevant data excerpts across the entire body of empirical data. We then looked for the relationship between codes to identify and develop our themes (Braun and Clarke, 2006). Due to the vulnerability of the project participants and sensitivity of the health data, all of the interviews and field notes were anonymized, encrypted and stored on a university platform that is not used for commercial purposes.

Theme	Code	Description
Socio-Emotional Behaviour, Interaction Effects and Reactions	Engagement	Underlying engagement and motivational aspects observed during the sessions and made visible in the interviews
	Unintended Movements	User behavior when interacting with the game that was observed but not anticipated when the game was designed
	Singing alone and in the Group	The different forms of singing in the different settings
	Facilitating Memories	Biographical statements fostered by the music
Social Aspects	Audience Participation	Reactions coming from the audience that led to joyful and emotional moments
	Role of the Caregivers and Relatives	Interactions initiated by the care-network
	Social support and Limits of Understanding	Social interactions and communication, as well as problems that occurred due to the complexity of the tasks
Physical Effects	Engagement	Different levels of engagement for the PwD, professional caregivers and relatives
	Movement	Movement executed through the music-game

Table 6: Coding scheme

System Evaluation

After the system had been deployed, the functioning and efficacy of the system was continuously assessed, refined and extended to reflect insights arising from observations of its use and feedback. Below we present the findings generated by the evaluation.

Socio-Emotional Behavior, Responses and Interaction Effects

The participants' motivation and performance were heterogeneous and often depended on their current condition. However, the participants visibly enjoyed the joint group exercises, though we quickly realized that a greater range of music was needed to prevent the game becoming repetitious. In the following sub-sections, we examine how the game was engaged with, the extent to which guidance was required and the role the game played in facilitating reminiscences.

Engagement in Music Activities

The participants' active engagement with the system in the weekly sessions increased each time the musical repertoire expanded. The participants did not necessarily walk as intended, but would listen to the song and move to it individually instead, recalling memories that were often core to ensuing social interaction. Well-known songs had a particular impact on motivation and cooperation. This was evidenced by the participants singing along together without needing to see the lyrics. A participant could choose a specific song or the group could choose it on their behalf, with their agreement. Sometimes participants would perform small side-steps, short dance moves, or even start dancing. Mr. P. and Mr. H., who usually complied with the game instructions, on one occasion started to dance spontaneously when another player started moving to the music. On another occasion, Mrs. U. stood up while someone else was actively playing and began to move in parallel, echoing the player's actions. In Mr. P's. case, his enthusiasm chiefly stemmed from an interest in sports. Having previously been physically active, he liked the games with music and additional movements because of the intense activity. A lot of the pleasure, however, was evidently a result of the novelty of being able to play music in day-care, of it being something other than the usual routine. Participants had sudden license to move around and dance and to engage in shared expression. The music-based activities generally created a happy and relaxed group dynamic in the day-care center and, most of the time, walking to the beat of a song caused no problem, moving Mrs. U. to comment that:

> *"It isn't really difficult. And I just stop if it's too much for me."*

As soon as a song started, people in the room began to sing along, especially if Mrs. S. was present. Mrs. S. had a strong musical background. She only needed the first notes of a song to recognize it, upon which she would immediately begin to sing, moving her upper body in time to the rhythm. This encouraged the other participants to join in, so she had a stimulating effect. We saw many instances where the participants motivated each other in this way and almost everybody sang along to the well-known songs. Their engagement with the music was also made visible by their clapping with the beat. When this happened the current player's movements often became more pronounced, suggesting that this brought the player added motivation. Mr. H., who did not show much interest in the game at the beginning, was increasingly encouraged by this spirit of participation abroad in the room. In the end, he spontaneously stood up to move to the music and even worked in a turn, commenting: *"Can we also add a turn here?"*

Although not a fixed feature of the game itself, singing along also happened in all three of the participating households. They knew many of the lyrics when they heard the melody and had great fun joining in. A physiotherapist who regularly visited the households also confirmed that the participants *"usually sang along [...]"*. In the case of Mrs. L, the physiotherapist and Mrs. L.'s granddaughter often sang along with her as well during the sessions: *"[...] the songs that both we and the physiotherapist knew"*. However, the role played by the granddaughter here proved to be especially important. Generally, the motivation to play in the households was variable and depended on the PwD's health status, daily routine, surrounding people, social circumstances and the participants' potential playing partners. Mrs. L. and her granddaughter, who lived in the same household, always played the game together. It was clear that the granddaughter was the driving force, displaying a motivation that then motivated her grandmother. In fact, Mrs. L. said at one point:

> *"My husband and I, we both couldn't dance. When we were at a party somewhere, I always said, come on, let's go to the middle, we won't be noticed there."*

This makes it unsurprising that Mrs. L. never played on her own. However, she always played when her granddaughter asked her to – regardless of any fatigue or knee problems. They used the system several times a week and members of the household documented the activities to record developments, making it possible for the granddaughter and Mrs. L. to see their progress and exercise accordingly. Mrs. L. said herself that she was "excited" to be able to use the game. Although the gameplay was driven by someone else, the clear social backdrop was that, by playing the game, the grandmother got to spend time with her granddaughter.

The Need for Guidance

A potential difficulty with games of this kind is that PwD do not always remember the functionality, so, they can never be expected to play the game unaided. This was made evident by occasional incidents during the sessions. Mrs. H., for instance, once ignored the moderator's efforts to get her to walk and simply started dancing, taking the moderator's hands so they could dance together.

An active part of the interface was picturing the participants as the needle of a virtual record player that either slowed down or stopped completely when the player ceased to move. However, this was not always properly understood. For instance, we had noted that Mrs. A. was very keen to play by the rules. Whenever it was her turn, she concentrated on walking on the spot to the music, not letting herself be distracted. However, on one occasion she stopped walking and thought that the game was completed because the music had stopped. When this happened again, the moderator explicitly asked her to start walking again. She then said: *"Ah, if you walk it gets louder again!"* Yet, in the following session she had forgotten and made the same mistake. In another incident, Mrs. U. initially stopped walking because she was mimicking the standing avatar, not realizing she could control its actions. Mrs. P. was also unsure about the avatar at the beginning, remarking that "*He's doing the same things that I do"*, so she started marching like a soldier. The notion of the avatar then had to be explained again.

These incidents imply that even basic concepts can be problematic for PwD. Recognizing that their movements can affect something on a television screen requires a form of reasoning that can escape them or be hard to subsequently recall. This implies challenges for future design for PwD because it raises difficulties with even seemingly straightforward assumptions on the part of researchers about what intelligible functionality might look like.

Aside from this, by walking on the spot, most participants ended up slowly moving forward towards the TV. This sometimes put them too close to the system, making the Kinect camera lose its tracking and bringing the game to a halt. This then confused the participants. When this happened, the users had to be asked to step back. It was noticeable, however, that participants who kept a chair next to them to prevent a risk of falling, rarely walked forward. Being oriented to the chair seemed to hold them in a fixed position. So, it can be seen that requests from the moderators were often necessary to keep the game going. An important part of the pleasure the PwD found in the game was being able to respond to the music in their own way.

Sometimes, of course, no amount of guidance can help. Faster songs, for instance, sometimes meant participants could not maintain the speed and were unable to finish the game. This was particularly so for songs with a faster basic rhythm and beat. The participants usually responded to this by adjusting their movements to the beat and moving more quickly and intensively, before giving up completely. Their reactions to having to stop were quite diverse. Sometimes they had to take a little rest, while other participants stepped in. On other occasions, they wanted to improve their performance and start the same song over again. Sometimes, rather than stopping entirely, if the song was too long and challenging, their steps would begin to drag towards the end. All of this adds up to saying that, to work as an exergame, a recurrent need for guidance, instruction and moderation, where difficulties are quickly recognized, would seem to be inevitable. Thus, it seems unlikely that these kinds of resources could ever work as free-standing technologies to be used by PwD on their own.

Facilitating memories

As most of the music was familiar to the participants, it triggered old memories. Participants with apparent memory issues during conversation, could often recount memories from when they had sung or heard a familiar song being played. On one occasion, when hearing a song, Mrs. I. said: *"I can think back to when I was 18 and we sang that"*. Another said: *"It has been 70 years since I sang that, as a young girl."* A professional caregiver visiting one of the moderated group sessions was very impressed by the impact the game was having upon people's recollection: *"I'd like to have something like that when I am old, but, please, with different music."* In Mrs. M.'s household, her husband said she was only active when she used the music room. Once there, however, she became visibly animated and moved as well as sang. On one such occasion, her husband said:

> *"She used to like to dance. She usually chooses well-known folk songs and plays around. She also understands that she has to move or the music will stop."*

Mrs. M. was the participant with the strongest musical background and had great enthusiasm for the game. She had sung professionally in the past and told us: *"I liked to sing, I even sang in a choir and I think that I have a nice voice."* Mrs. M. remembered many of the songs she had sung and apparently had not forgotten the lyrics. In the final interview Mrs. M. said: *"Oh, I know so many songs. [...] I was in a choir."* The radio was usually turned on in Mrs. M.'s house. Her husband said the radio was for him, but Mrs. M. often reacted to it and sang along to songs she knew:

> *“She sits here in the mornings for breakfast and moves to the music, if she’s in a good mood.”*

It is hard to over-emphasize the impact that familiar music could have upon the PwD. Overall, five participants had been in choirs and had danced, both as amateurs and as professionals. Relatives described how they used music, especially old songs, to remain close to their partners and parents who sometimes didn’t otherwise remember them. In the day-care center, many activities involved singing and getting the PwD to slowly move to music. Professional caregivers consider music an important source of communication and emotional engagement with PwD and draw on it extensively. In one household, Mrs. S. said *“I rather like the music marathon”*, but she also wanted to be able to adjust the music to her own preferences. So, she continued by saying *“[...] but this kind of music, I mean I am only 75, not 85... Connie Francis, love is a strange game, I don´t care about this music.”* Professional caregivers believe music encourages positive feelings and experiences. One caregiver said:

> *“Music is a core concept of activation, so I feel music is the method with which you can get the most affect and where you can get it the most easily”.*

A vital part of all this was how the participants were prompted by the music to recollection. Mrs. T., for instance, said: *“Oh, it's a shame it's over. The songs bring back memories”.* Clearly, however, this depends on the PwD having particular associations with the music. So, the choice of music is critical. However, alongside of this, there is a need to recognize that, in day-care centers, there is a public aspect to such games that also plays an important role and that the choice of music may also need to attend to this. Thus, we observed that it was not only the participants sitting in front and actively participating in the sessions that took part. There were also spectators at the back, who often commented positively on the game or sang along. Indeed, one visiting guest mentioned that: *”If everyone had sung earlier there would have been no war”,* and another non-regular guest stated that*, ”the game is good for the body and keeps you fit”.*

Figure 21: Interaction in front of the System

Social Impact

The music game had a range of social impacts that often gave those involved a visible group cohesion that was otherwise absent. The participants in the moderated group sessions from the day-care center who had been involved from the start went to almost every session and we were told they always looked forward to them. Increasing enthusiasm for the music room and social participation were observed in the day-care center as the project progressed. At the start of each session, the participants were already in the room waiting for it to begin rather than drifting in. An exception to this was that Mrs. A. and Mrs. U. liked to take walks during the summer, but they later said that they regretted missing the beginning of the exercises. Mrs. H., who was keen to join in, afterwards commented:

> *“The mood is good and I feel good. It’s completely different here with the singing and the music.”*

We also noticed that participants with a more dominant character developed into group leaders, taking the lead in the sessions. These ”leaders“ were able to motivate other group members, were very performance-oriented and played the game with ambition. One such participant gave other participants tips and instructions on how to carry out tasks and sought to excel in the exercises.

Audience participation

When a well-known song was played, the participants sang along. It didn’t seem to matter if they followed the lyrics or kept time. Instead, they often sang ahead of the music and would only notice they weren't in time at certain points, such as the refrain, at which point they attempted to correct themselves. Music not only animated participants to sing along, it encouraged them to move. Otherwise passive participants were often seen to move to the music, swaying on their feet or clapping or moving in some other way. Some had a pronounced sense of rhythm and made this their focus. Mr. P., for instance, once said:

> *"I want something with rhythm."*

Others, such as Mrs. H., were more focused on the melody. The participants were also keen to sing at home. Mostly the participants themselves drove this, though Mrs. M's husband did sometimes ask if they could sing together. However, the enthusiasm for this kind of participation was not universal. Mrs. L.'s grand-daughter once asked her to sing during the observations, but her grandmother declined: "*No, it's fine like this, I can't sing that, you have to sing."*

During the group-sessions in the day-care center, professional caregivers or other guests often came by to watch. A professional caregiver commented once to the participants that: *"You have to be careful, otherwise you'll be like children again"*. Generally, the professional caregivers recognized the added value of the game and used it to attract new participants – even without dementia. Over the course of the evaluation, the group dynamics became increasingly pronounced, with the participants supporting each other, cheering each other on and playing and moving together. This strengthened the social environment and the PwD's social engagement enormously. One professional caregiver was moved to say:

" I believe that this is also good for them as a group, seeing them cheer each other on and give each other positive feedback. With music it always works well".

Other participants were also encouraged to participate due to the increasing group dynamics and interactions. One non-regular day-care participant commented: *"The atmosphere is good and I feel good, here you can experience things very differently with the singing and the music"*. However, while the group dynamics had a motivating and activating effect on many, there were also some contrary reactions. Mr. H. for example stopped from time to time during the game, to talk to others in the group and only continued to walk when the researcher asked him to. Then, when something new came to mind he stopped again to talk.

Often the participants were actively giving each other instructions. As soon as someone did not know what to do, another participant would tell them to move. Beyond this, the relationship between the researchers and the PwD developed over time. The PwD began to look forward to not just the game, but also to the contact with the researchers. This was confirmed by the day-care staff: *"So, yes, they are also waiting for you as people. The human way you conduct the group-sessions, but also the way you built the game, is thoroughly attractive to them"*.

The role of informal caregivers and relatives

In Mrs. M.'s household, her husband was impressed by the technology and used it himself to train on a regular basis. Having explored the range of options, he tried to get his wife to play all of the games. However, Mrs. M. needed no extra encouragement. Music had played an important role in her past, so she was fully motivated to get involved and, as soon as the game and music started, she played with enthusiasm. Mrs. M.'s behavior seemed to change the moment she was in front of the game. She sang along, moved and expressed recollections. With other games she was less motivated and just wanted to get back to bed, but with the music room she stayed and even sang songs from memory with her husband. It was particularly striking that Mrs. M. was the only participant who chose her songs deliberately and in cooperation with her husband. Her husband operated the system, but she said which songs she wanted to hear.

As noted, for Mrs. L., the system allowed her to spend more time with her granddaughter. They played together regularly, with the granddaughter challenging her grandmother and motivating her to exercise. Mrs. L. enjoyed this time with her, though sometimes it could leave her exhausted:

> *"Now I have to get up again, even though I stood the whole morning, but now I have to take my medicine."*

Mrs. M. often didn't remember having played the game and could relive the excitement of playing it again and again. Mrs. L., however, remembered the different sessions and needed her granddaughter's encouragement: *"Start walking, grandma."* As things proceeded, it became clear that Mrs. M.'s household had developed a lot of enthusiasm for the project. It even extended to her circle of friends and neighbors, who were also invited to share the experience. Mrs. M.'s husband not only used the tablet to start and navigate the system, but also to film his wife while she was singing and playing. In one interview, he showed us a video of his wife where she wasn't playing the game, but rather in the kitchen where she regularly spent the morning singing, with and without her husband. When she saw herself singing, Mrs. M. started to sing along and her mood seemed to lighten. Her husband said he also showed the recordings to their children, who couldn't believe the transformation that came over their mother when she was playing. Sadly, although the relatives in Mrs. L. and Mrs. M.'s households evinced a lot of support and enthusiasm, in Mrs. G.'s household, there were unresolved private issues that resulted in the relatives' having little time to concern themselves with the system.

Social support

In relation to the group dynamics, it was found in the moderated sessions in the day-care center that several PwD established contact and developed new friendships with other participants. They gave each other tips for the execution of the required movements in the game and cheered and applauded each other when they managed to finish a round of the game successfully. Over the course of the evaluation period, we noticed that some participants were not only already in the room before the start of the workshop, some were even waiting at the entrance for the researcher. This was also noticed by the professional caregivers who had a positive view of the impact of the music–game and the sessions and felt that a long-term installation of the system would make sense. The day-care workers also mentioned that the introduction of the system and the workshops was encouraging group formation, which was then lasting beyond the workshops and initiated further conversations, even after the game sessions. The groups formed in the sessions tended to stay together in the day-care center outside of when they were using the system and they often asked the professional caregivers about the time of the next workshop. The caregivers commented that the PwD were not only interested in playing the game, but also appreciated the interpersonal relationship they were establishing with the research project's researchers. One professional caregiver said: *"I know that some of them always used to make dates or arrangements to walk in the garden and then they came to me together and said: is the university coming back?"*

In the day-care center, while the game was all-consuming for some, others were occasionally more interested in other things going on around them. Mr. P., for example, would sometimes stop and stand still while talking to others in the group. Only after hints from other participants, did he start walking again. We often observed participants giving each other instructions during the game. These were particularly forthcoming when the player was not playing by the rules or was uncertain, such as the instances where players struggled to understand the virtual avatar mentioned above. Sometimes this support was more active and took the form of one of the others moving to a song to encourage a reluctant or confused participant. In the case of Mrs. T., one caregiver said that she *"could hardly do any exercises herself in terms of abstraction and understanding".* Yet, given the right kind of encouragement, she could still get involved, as the caregiver went on to explain:

> *“[...] When a well-known song was played and Mrs. E. walked along to it, you could see how Mrs. T. reacted to the lyrics and I saw in her posture that she sat differently and she sang along as though she was as unaffected by the illness...”*

Physical Aspects

The physical impact of the music game upon the PwD, although broadly positive, was variable. In many cases, this was down to the orientations of others around them and their willingness to invest effort in encouraging the PwD to move. Relatives, for instance, could take on very different roles.

The driving force in Mrs. M.’s household was her husband. He made sure she was motivated and engaged. This seemed to pay dividends, with her physiotherapist saying *“[...] Mrs. M. was especially motivated using the music game. She stood up, moved to the game, sang and danced. She was very enthusiastic about it.”* Her husband’s interest stemmed partly from his own appreciation of the game. When Mrs. M. lacked the will or capacity to play, he trained by himself: *“I use the game for myself to stay fit, when she’s not in the mood.”* Mrs. M. said *“I used to sing and dance a lot, alone and with my husband. I could always dance. So, when I was healthier I could do it better, but I was very happy to do it again. Yeah, well, that's why walking to music is nice. I love music.”* She also suggested improvements: *“Dancing is life for me and if you could dance to the music instead of walking on a spot that would be even better.”*

Mrs. M.’s husband said with respect to the experiences of his wife towards the game that,

> *“The music game is good; my wife likes to do that. She also likes to sing and then she sings along. She used to like to dance, she usually takes the well-known hits and then she moves and understands that she has to move or the music will stop. So, she understands the principle.”*

He particularly used the game to get her moving in the morning: *“Music Marathon gets started first, as an attempt to motivate her and get her to play first thing in the morning.”*

The granddaughter took the lead in Mrs. L’s. household. She always chose the music and the songs she didn’t like weren’t played. The relatives in Mrs. G.’s household had little influence because they didn’t have the time. This made Mrs. G. wholly dependent on her physiotherapist for her engagement with the game. Thus, she got less exercise than the PwD in the other two households. However, her physiotherapist did say that:

> *“Mrs. G. was able to sing along to most of the songs, so it was definitely positive.”*

The usage log-files for the exergame show that Mrs. L.'s household used the system frequently and intensively. In Mrs. M.'s household it was played less and it was also hard to distinguish whether it was her or her husband playing the game. The focus in the households was more squarely upon fitness. In the day-care center there were other concerns. In the households, the PwD were usually alone in front of the TV and only one other person was typically present. Thus, the group dynamic observed in day-care was missing in the domestic context, (partly) limiting the game's more social aspects. Without the various distractions and interruptions commonplace in the day-care center, the participants in the domestic environment tended to focus more on the correct execution of the tasks (e.g. walking at the same pace until the music stopped) and the correct movements (e.g. alternating walking movements on the spot).

With regard to combining music and movement, Mrs. P. said: *"So, in terms of physical exercise, I really like the music marathon, because you have to run straight away, one after the other, and that makes it more active."* These games can sometimes provide time out for relatives. However, the daughter of Mrs. P. commented *"[...] it was additional work for me"*. Despite this, she said that her mother

> *"[...] just gets involved in doing things like this. Because she's usually at everything: fending things off first. So, that she was even willing to do it was really impressive. And I haven't actually seen her so willing since my father-in-law died. And I found that really interesting. Usually, no matter what, even if my mother just can't handle the can opener, one of us has to come. But when doing the game, she wasn't afraid of it. Well, that was one of the most interesting things about the whole thing, that she really got involved. And I think if that were really easier to use, she'd do even more."*

Professional caregivers and the participating music therapists generally recognized the benefits of music. Just some of the comments made by the professional caregivers we encountered were:

> *"Music activates everyone. With music everyone sings and claps along",* or *"with music even unmotivated people can be activated"*, with music encouraging *"dancing or running movements in game activities"*.

Some of the PwD were well-aware of the effect that playing the game could have upon them. Mrs. Q., for instance, said: *"With music, you can orientate yourself by the beat. We have to move to stay active. Simultaneous movement and singing is also possible."* The music room brought movement, memory, relaxation and fun together in one activity, without emphasizing notions of competition or performance. Thus, the need to progress through levels was dispensed with. In later changes, users no longer had to run on the spot, but could move freely to the rhythm or dance. This made the focus on enhancing motor skills recede conceptually into the background, whilst still being retained.

Figure 22: Participants dancing together with a moderator

Discussion

In the following section, we discuss the results and focus on the individual and social benefits of using the music-based exergame. We also consider the practical aspects of undertaking this kind of research and the limitations and challenges confronting design in this space.

Effects of music

Together, the literature and the results of this study make clear the potential of exergames combined with music to activate PwD and enhance their social engagement. Music is a motivating force for people throughout their lives. For PwD, we have seen how music can prompt a range of memories that might otherwise seem lost. Popular music from PwD's youth is especially effective at evoking memories and we found that this can be a starting point for interaction with other people during game sessions. In both the day-care centre and the households, the social aspects of playing the game became especially important. There was clear pleasure to be obtained in singing along together, clapping together, moving together and encouraging one another in their participation. In the households it became a systematic vehicle for interactions with other family members that might otherwise only arise by chance. The very fact that the game was planned for and made a part of the routine allowed for these pleasures to be looked forward to by all involved, the cared for and the providers of the care. Our initial focus was on using music to maintain the physical capacities of PwD. It was assumed they would largely be playing the game on their own, whilst giving caregivers and relatives ‘time out’. This notion was set aside over the course of the study. Instead, we realized that participants need a social arena in which to play, where they can share experiences prompted by the music and the game-play itself. So, in the end, the game became a space to explore with others and to discover together long-term memories and feelings.

Prior studies (Aldridge, 2003; Brotons and Koger, 2000; Cuddy and Duffin, 2005; Foster and Valentine, 2001; Lord and Garner, 1993; Polk and Kertesz, 1993a) have suggested that using well-known music can facilitate recollection and stimulate the long-term-memory of PwD, while reducing symptoms of depression, counteracting isolation and increasing their ability to make decisions (Hannemann 2006; Schmitt and Frölich 2007). This was partly confirmed by our own work. The above findings show that the game did indeed connect participants in the day-care center and families and friends in the households, initiating social experiences and fostering social interaction. We noted above, however, that the correct choice of music is critical. The specific music that has an impact is a function of the age-group the PwD belong to and may also be bound up with specific localities and cultural backgrounds. Musical interventions have also been shown to improve the verbal capabilities of PwD (Cuddy and Duffin, 2005; Suzuki et al., 2004). Certainly, in our own work we did find that they became more communicative, both with one another and with others. We observed numerous instances where PwD were visibly enlivened by the playing of music they recognized. Other studies have found that listening to music can have an impact on PwD at a physiological, emotional and mental level (Hesse and Bernatzky, 2005). In this study, to put it quite simply, the music game made the PwD visibly more alert and manifestly happier.

What became specifically evident in our study was the extent to which the music-based exergame affected not just the individual situation of PwD but their social life and environment. This has been less discussed in the literature. Social effects took place at an individual and group level and not only during the game but beyond it in terms of how people organized themselves and were motivated by their caregivers to participate. We also saw the participants regularly reminiscing with one another during and after finishing a game. This took the form of both spontaneous stories about their past and reactions to memories triggered by a song. Whilst we have only had the space here to present a few isolated examples, we noted that the game often generated conversations, among both the participants and their caregivers. So, the game was productive of social interaction far beyond its own confines.

Singing along during the game was particularly motivating for engagement with the game and the movements. Singing in this way had a visible impact on the well-being of PwD. Singing and dancing together was productive of further interaction amongst them and created a relaxed group dynamic, making it easier to communicate with them and encourage them towards self-expression. Something that should not be under-estimated in terms of its importance was the extent to which not just participants but caregivers derived pleasure from it all. Relatives, grandchildren and professional caregivers all developed an interest in using the game as a motivating instrument. A major outcome was that PwD and their relatives found ways of playing the games together. Thus, relationships that were otherwise challenged by dementia were strengthened, making the music-based exergame a potential starting point for other collective activities. A critical effect was that playing the game supported the ongoing participation of PwD in family life. These potential intergenerational and intra-familial aspects need to be duly noted and properly considered in the ongoing pursuit of technology design and research with PwD. It should also be noted that, as caregivers ultimately play a key role in facilitating and maintaining access to such technologies, these outcomes provide for their longer-term sustainability.

Music can have an impact on PwD and their social environment at different levels. Zampolin et al. [2015] have already noted that music can have a positive and uplifting effect, not only on PwD themselves but upon their surrounding social milieu (Zampolin, 2016). Whilst not something directly measured during this study, other research regarding the use of exergames by PwD suggests that they can stimulate self-confidence and help to improve PwD’s execution of everyday activities (Blankevoort et al., 2010a; Göbel et al., 2010b; Kemoun et al., 2010; Polk and Kertesz, 1993b)Anecdotally, the comments from the professional caregivers and physiotherapists reported above indicate that the music-based exergame was also having this effect. More than this, many of the PwD proved to be capable of recalling a large repertoire of lyrics and melodies. Not only did this underpin their interaction with other people, it also underscored the findings of previous research that music can provide a way of tapping into aspects of PwDs memories untouched by dementia, providing a resource for emotional engagement (Omar et al., 2011).

Effects of Movement

This work has affirmed the findings of Göbel et al. [2010] that exergames – especially ones using music – can provide PwD with additional physical movement and emotional activation on top of their daily activities (Göbel et al., 2010b). Göbel et al. [2010] appealed for more individuality in exergames for older people to ensure they are neither physically nor mentally under- or over-burdened, with the system adapting to their needs (Göbel et al., 2010b). In the music room, individual capabilities were considered in the game mechanics. Thus, the speed of movement did not have to match the rhythm of the music played. Early observations in the evaluation quickly showed that imitating the Avatar's movements caused confusion among active players. Occasionally they tried to adapt to the movements of their virtual image. The avatar's running style was therefore changed and, as he no longer imitated the exact movements of the user, he adopted a more sporty, pre-defined running style as soon as the participant started to walk in front of the camera. This change prevented wrong movement detection and tracking and the potential for strange avatar presentation. After the change another interesting advantage could be observed. Due to the new independent pre-defined walking style (without occasionally strange misdetected movements due and caused participants confusion), users were able to move more individually in front of the camera to make the avatar walk on the screen. This meant that the moderator did not have to constantly ask the participants to walk normally or to lift their knees higher. This way the game had a higher fun factor for the participants and offered more room for individual movement because the PwD could control this for themselves. This also had the other desirable outcome of enabling the system to adapt more effectively to the PwD's needs. As there was no level structure, individuality was also provided for by letting each participant choose their favorite songs and get involved in a different way, through movement, listening and/or recollection.

Lilla et al. [2012] came to a similar conclusion when they studied people with Parkinson's, with music helping them to perform their movements more easily and rapidly and with greater motivation (Lilla et al., 2012). The exergame presented here adopted a similar approach to motor skills to that used by Lilla et al. by trying to promote a connection between movement and memory. The participants used physical movement to keep the music running, while focusing on the music and letting it prompt memories, thereby activating cognitive and emotional engagement. Whilst engaged emotionally in the game, the correct execution of the necessary movements (alternate raising of the knees) became less of an issue, hence our observations of typically unresponsive participants being prompted to spontaneous action. We saw participants doing things such as incorporating their own sidesteps and minor dance moves or walking more quickly. Generally-speaking, we found that the emotional engagement of the PwD pulled them along and made the effort involved in moving less of a focus for them. On top of this, Göbel et al. [2011] found that many seniors are willing to use modern technology, usually out of curiosity or for contact with younger generations (Göbel et al., 2011). We saw this ourselves in both the day-care center and the households. In day-care, the participants were delighted to be dealing with young moderators. In Mrs. L.'s household, it became a key resource for her to engage with her granddaughter.

Individual and Socially Meaningful Activities in Different Settings

In the same vein as Phinney et al. (2007) have previously noted, we can confirm that the effects observed in day-care due to the introduction of the system included the forming of new social contacts and friendships and therefore a sense of connection during and even after the moderated sessions in the day-care center. If one of the regular participants was missing on a training day in the workshops, they were directly inquired about, because, according to the PwD "*something was missing*". This strong group cohesion and the friendships formed in the workshops continued after the end of the sessions. As also found by Phinney et al. (2007), the PwD in day-care were manifestly comfortable in a group with other PwD and felt a certain sense of belonging through the familiarity of the social and physical environment in the sessions. Nevertheless, we also found that the PwD expressed embarrassement about using the system and a standing in the middle and solving tasks in front of all of the participants in the workshop. However, the encouragement of the other group members, especially the regulars, helped them to overcome these sentiments and try out the games. In day-care, another group effect could also be observed. We noted in the findings that, PwD with a dominant character tended to develop into group leaders, taking the lead in the games and trying to motivate the others to perform as well as possible. This ambition apparently had an infectious character, as the group leaders clearly generated a greater willingness amongst the others to succeed. What is especially interesting about both this and the occasional feeling of embarrassment is that it makes apparent that, as a group, the PwD were evincing a sense of social accountability, rather than remaining isolated within their own concerns. This is a powerful force for keeping PwD engaged and aware of the other people around them. It also provides an effective basis for broader patterns of interaction, as we observed. Thus, there is more to be said here than simply that music is an effective tool for engaging PwD. The music-based exergame became a locus for patterns of social engagement, accountability and interaction that extended far beyond just the game itself and the immediate environment. In other words, playing the game was socially meaningful and made the PwD socially functioning individuals in ways that dementia is typically seen to erode. It might therefore be expected that the deployments in the households would have been less successful on this score. However, we also noted in the findings that the game had a similar effect of promoting intrafamily social interaction, even to the point of individual PwD being seen as more fully functioning family members.

Bejan et al. (2018) found in their study regarding the use of ICT-based reminder systems, that PwD enjoyed using technology more active in group settings than in individual sessions. From the perspective of our evaluation study, the fun factor and the social experience arising from using the system were crucial factors. In some cases, the actual game receded into the background and the focus shifted to the pleasant and exciting group dynamics. During the group sessions in the day-care center, the individual participants became active, cheered each other on and interacted with each other. As noted, this effect was also noticed in the households during the individual sessions in a weakened form. In their study, Pinto-Bruno et al. (2017), examined the effects of ICTs on the social health of PwD. In this context, they stated that ICT can promote social participation and support the development of social networks. As mentioned in the previous section, different group dynamic effects and the formation of social networks between PwD and the researchers were observed in the day-care setting that led to an increase in social contact, which PwD manifestly perceived and wanted to retain.

The core point to grasp from this as a design community is that, for these effects to be available, the games need to be enacted in a social environment, be that in groups in day-care centers or in living-rooms with family members and friends. This means thinking beyond the games and activities themselves to thinking about the kind of social environment they will be performed in and whether this is a social environment that is generative of this order of social accountability and interaction. It would be wrong to argue that engaging with these kinds of games in settings where the interaction is only with health professionals is ineffective. We saw in the case of Mrs G. that her interaction with her physiotherapist was still productive to some degree. However, when the interaction is with someone who will be leaving at the end of the session and who you will not see again for several days or even a week, this is clearly different to interacting with people who are consistent part of your social milieu. This actually implies that there is a certain overhead for caregivers when these kinds of technologies are deployed. An appropriate social environment does not come out of the box with the technology, it is incumbent upon other people to provide that environment and, typically, that task falls to caregivers.

It is therefore not especially surprising that the results suggested that the use of game did not lead to some kind of relief for the caregivers in the households, even though it did create room for social engagement and positive experiences. This was, of course, in the first instance due to the fact that the PwD could not operate the system independently and needed the help of their relatives to start and use the system. This means both learning how to operate the system and then remaining present, with no time out. In the households, this was aggravated to a certain extent by the fact that some of the relatives and caregivers were also of advanced years and, according to their own statements, had had little contact with ICT. In our own deployment, however, we also noted that an interpersonal relationship was established between the researchers and the participants as well as the caregivers. The participants looked forward to the sessions, not only for playing the game, but also for the contact with the researchers. Furthermore, the caregivers reported that the PwD remembered and looked forward to the researchers coming in. This implies that it is not necessarily the case that intermittent visitors are unable to promote the kinds of social interaction that can remain socially meaningful beyond the confines of the game. Rather, it would seem that interaction with researchers provided a particular kind of social dynamic that was generative for the PwD. This may be because the researchers were something other than the various kinds of health professionals the PwD encountered on a routine basis and were willing to engage with them in a different way, but our own materials offer nothing more here than a recognition of the phenomenon. This is something that begs for further research.

Limitations

One of the main challenges confronting this research was dementia itself and its highly individual course. It was impossible to predict how dementia would develop among the project participants. Mrs. U. and Mrs. I., for instance, were always involved in the day-care sessions, but had to leave day-care during the project for health reasons and could not see the study through to its end. Other participants were temporarily absent from time to time. It is also difficult to contact PwD and their caregivers and even more difficult to acquire potential participants for a scientific study. In our case, we specifically needed participants diagnosed with early to moderate dementia who were capable of understanding the tasks and physically able to interact with the system. Recruitment was made more difficult by the fact that PwD and their families have to deal with a lot of organizational and emotional turmoil after diagnosis. Dementia can also develop very rapidly and other age-related diseases can accelerate its progress.

So, it was never possible to be sure how our relationship with the participants and their caregivers might unfold.

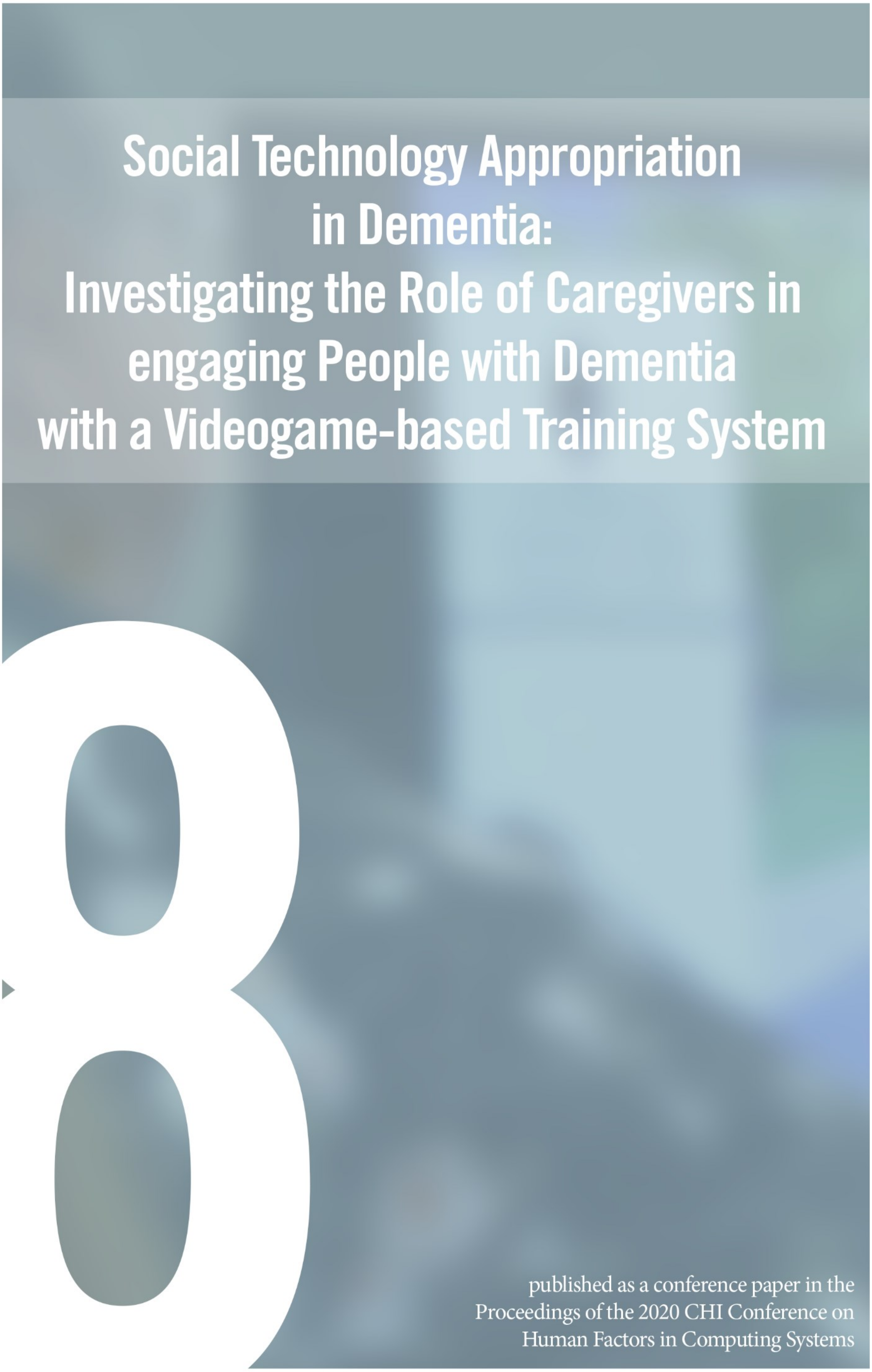
Contacting relatives could be an issue in its own right. If the participants were acquired via a residential group or day-care, there was usually no contact with their relatives. The few who were contacted canceled due to lack of time and the stress of everyday life. Thus, we failed to involve any of the relatives of the PwD we were studying in the day-care setting. Professional caregivers from the day-care center took over the role of interested others. A related problem is that contact with relatives is important for interpreting, deconstructing and unpacking the things PwD say, especially in interview situations, because feedback from PwD can be hard to understand for those who don’t interact with them on a daily basis.

Furthermore, with regard to the use of motion-based technologies for PwD, Dove & Astell (2017) have suggested that the Microsoft Kinect is well-suited for use with PwD. This is something we can only partially confirm. Participants with dementia had no problems using the Kinect’s gesture control and it was found to be intuitive and easy to use. However, in the original prototype system developed prior to this study, the Microsoft Kinect camera recognition was one of the main sources of error and was a source of frustration for many participants in that study. In this study, too, the Kinect camera caused some issues. As a result of constantly walking on the spot, almost all participants found themselves moving forward unconsciously. However, as soon they got too close to the Kinect camera, it lost its tracking and the moderator had to ask the participant to take a few steps backwards again. We saw above that some participants managed to offset this by using a chair as a fixed orientation point. Other aspects of the technology also presented issues. As the game was only a prototype, there were problems with understanding the technology and operating it. Most PwD and their relatives had had little experience with modern technology, making them dependent on external help. The study also found, as with Vaziri et al.’s (2016, 2017) broader observations of older adults, that PwD using and interacting with exergames need a lot of guidance and feedback to be able to participate. There are two particular ways in which this feedback needs to be articulated: both by the system itself; and by other people who are present, with system-only feedback typically being insufficient (Larsen et al., 2013; Lazar et al., 2017a; Morrissey et al., 2016b; Müller et al., 2015). We have already seen that the participants needed to think of themselves as the needle of a record player while walking. If they failed to walk, the music became slower, faded out and finally stopped. Some of the participants struggled to understand this, even after many sessions. As a result, the moderators had to motivate some of the participants to keep moving. Some of the participants were also not aware of their relationship to the avatar. Indeed, the reasoning involved in relating oneself to a figure on a screen is non-obvious if one has never been previously exposed to it. In the case of the PwD, initial exposure was not necessarily enough. There was never any guarantee that their understanding would be retained between sessions and it proved to be the case with some participants that they had to have things explained anew almost every time they used the system.

Finally, it was generally difficult to obtain new ideas or design implications directly from the participants. They often held back during interviews or claimed that they had no idea. We were therefore dependent on participant observations and information acquired from relatives and professional caregivers to get a sense of their preferences. During the game the participants could be questioned more casually and they would sometimes pass comment unprompted. If asked explicitly, however, no concrete answers were usually forthcoming. This makes it hard for researchers to find a balance between supporting PwD and influencing them (Lindsay et al., 2012b). During the observations, some insights could be gained by observing the PwD interacting with the system and with others around them. These limitations make it essential to involve family members, caregivers and other stakeholders in the design process. Thus, while the interviews often produced little feedback, the use of a PD approach with a broader set of actors was more successful.

Conclusion

The results from this study have illustrated that music-based exergames create opportunities to foster memories, initiate social interaction and increase physical activity for PwD. Initial findings were drawn upon together with insights from various interested parties and professionals, including care-home staff, music therapists, sports scientists and medical specialists. These provided a preliminary set of requirements upon which a pre-existing exergame was adapted to promote PwD engagement in music-based activity. Over the course of a subsequent 4-month evaluation, the initial prototype was iteratively refined to tailor it more closely to the needs of PwD and their caregivers. The exergame was observed to have positive social and physical effects in both day-care and household settings. Our study served to both, confirm existing observations regarding the potential of music to enhance the everyday lives of PwD and to expand upon them. In terms of technical development, the music room brought together the established benefits of exergames and music-related activity. The deployment of the technology was carefully observed and documented over an extended period, providing scope for it to be further developed and enhanced. Of special importance here is the way in which the music room provided a means of enhancing the social engagement of PwD with their own families, with their professional caregivers, and with a variety of external parties such as other day-care guests, visiting physiotherapists and music therapists. It is hard to over-emphasize the value brought to all of these parties by facilitating this kind of engagement. Furthermore, this kind of engagement can be consistently supported, turning it from a one-off intervention into something that can provide a vibrant living conduit for interaction with a community that is notoriously ‘hard to reach’.



Social Technology Appropriation in Dementia: Investigating the Role of Caregivers in engaging People with Dementia with a Videogame-based Training System

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SOCIAL TECHNOLOGY APPROPRIATION IN DEMENTIA: INVESTIGATING THE ROLE OF CAREGIVERS IN ENGAGING PEOPLE WITH DEMENTIA WITH A VIDEOGAME-BASED TRAINING SYSTEM

Abstract

There has been increasing interest in designing for dementia in recent years. Empirical investigation is now needed of the long-term role of caregivers in appropriating ICTs into the complex daily life of people with dementia (PwD). We present here the outcomes of a 4-month evaluation of the individual, social and institutional impact of a videogame-based training system. The everyday behavior and interactions of 52 PwD and 25 caregivers was studied qualitatively, focusing on the role played by caregivers in integrating the system into everyone's daily routines. Our results indicate that the successful appropriation of ICT depends partly on the physical, cognitive and social benefits for PwD, but especially on the added value perceived by their social care-network. We discuss the need for design in dementia to develop more socially embedded innovations that can address the social actors involved and thus contribute to practical solutions for professional and informal care.

INTRODUCTION

Dementia has commonly been characterized as primarily a clinical condition (Cunningham et al., 2015; Sathyanarayana Rao et al., 2017). However, a paradigm change is occurring and there is a shift towards a less medical and more 'social' view of dementia and the well-being of PwD (de Vugt and Dröes, 2017; Dröes et al., 2017; Kenning, 2018; Kitwood, 1997; Lazar et al., 2017a). The socio-emotional and psychological impact of dementia on the life of individuals and their social network has been relatively neglected. There needs to be a better understanding of these aspects if technology is going to be appropriately designed to support all parties concerned successfully. Information and communication technologies (ICT) have the potential to deliver support and promote social wellbeing and physical performance for PwD and their caregivers (Brankaert et al., 2019; Hodge et al., 2018; Houben et al., 2019; Lazar et al., 2017a; Morrissey et al., 2016a; Morrissey and McCarthy, 2015; Siriaraya and Ang, 2014; Welsh et al., 2018). The majority of dementia-related technology focuses on their safety, physical and cognitive stimulation and entertainment (Lorenz et al., 2019). In this regard, videogames, and in particular exergames- motion games based on existing technology where users are motivated to exercise through a combination of fitness exercises, gamification and computer games- have recently shown considerable promise. Studies show that they can lead to improvements in fitness, adherence and balance, regardless of age (Anderson-Hanley et al., 2012; Colombo et al., 2012; Garcia et al., 2012; Göbel et al., 2010a; Ogonowski et al., 2016b; Vaziri et al., 2016a).

There are relatively few HCI studies that focus on how care partners perceive technology while it is integrated into the daily lives of the people they care for (Arntzen et al., 2016; Holthe et al., 2018). The implication of this is that the successful positioning of ICT-based systems in PwD's daily lives requires systematic evaluation that focuses on both the interactions of the PwD themselves and their caregivers (Chen et al., 2013; Czaja and Rubert, 2002; Kolanowski et al., 2018). Caregivers need to be able to see the value and purpose of a suggested technology for it to be incorporated into the PwD's and their own everyday life and work structures in a sustained fashion. There is relatively little research dealing with the potential of such technologies with regard to long-term ecologies of meaning and use and the appropriation strategies that develop. The views and perceptions of relatives and professional, carers, who are the main stakeholders in the implementation of ICT in PwD's daily lives, are pertinent here. How these systems are perceived, appropriated and integrated into domestic and institutionalized care settings, then, is a vibrant issue (D'Onofrio et al., 2017; Unbehaun et al., 2018a). More multi-disciplinary and holistic approaches to exergame design that take into consideration the multiple intersecting aspects of a caregiver's life are desirable(D'Onofrio et al., 2017; Holthe et al., 2018; Stowell et al., 2019).

In this paper, we report on the results of a 4-month evaluation study with 52 PwD and 25 caregivers with an ICT-based training system to support PwD's activity. The system and related exergames (strength and movement, coordination and balance, and cognition and creativity) were developed, iteratively tested and redesigned with PwD and their stakeholders over a period of 2 years. The system's design drew upon interdisciplinary academic domains, such as sport and nursing science and integrated for different ideas (activity, cognition, creativity) based on well-established interventions that are already practiced in different care settings. In our study, informal and professional caregivers functioned as technology mediators. To begin with, they used the system without any regular support from researchers. We therefore focus here on the social appropriation and perception of the system by these caregivers. This delivers novel findings with regard to social appropriation of technology by caregivers. The subsequent discussion is centered around the following research questions: (1) What processes are recognized by caregivers to play an important part in the social appropriation of technology? (2) How exactly are systems socially appropriated and contextualized, i.e. what social factors and characteristics encourage a willingness on the part of caregivers to integrate systems into everyday life?

Related Work

Designing ICT-based systems for PwD and their caregivers requires that researchers and developers explore how dementia impacts the social life of the individuals concerned and what activities can impact the development of dementia. This can then serve to support meaningful interactions for all parties concerned. In this section, we examine previous work regarding ICT for dementia, sense-making and sustainability and look at the corresponding challenges faced in daily life, especially for informal and professional caregivers.

Diverse Perspectives of Dementia

Dementia not only compromises individual people's physical welfare; it also affects their social life and their relationship with others around them. Its impact on individual families and on social and (health-)care structures can be huge (Brodaty and Donkin, 2009; Colcombe and Kramer, 2003; Coon and Evans, 2009; de Vugt and Dröes, 2017; Schulz and Martire, 2004). The behavioral changes in PwD can confront relatives with emotional and organizational challenges they are not fully equal to (Schorch et al., 2016). Dementia can lead to a loss of primary bonds and a need for comfort, identity maintenance, and emotional, physical and social support, (Kitwood, 2013). PwD are not a homogenous group, have different needs at different stages, and come from diverse family and/or institutional situations. The need for a person-centered approach is paramount (Alheit et al., 2015). What this entails, however, can be subtle. The evidence is clear that PwD can still recognize their own emotions and the emotions of others around them and can correctly interpret emotional prosody (Kiewitt, 2014). Quality of life and maintaining independence are central, but, while people with dementia may not necessarily see themselves as ill, the focus of relatives may be more upon their cognitive and physical condition (Mokhtari et al., 2015). For caregivers, this can lead to The stress, depression and other medical problems. In addition, families often retreat from their wider social circles because of the negative character changes PwD can exhibit, resulting in social isolation (Schorch et al., 2016). A large part of the care PwD receive, especially in the early stages, is provided privately, in the home environment and, in many cases, by family members who may themselves be elderly yet, increasingly, still at work (Dove and Astell, 2017; Ruan et al., 2015; Sörensen and Conwell, 2011). Overall, the above-mentioned phenomena can result in a much lower quality of life for caregivers (Sütterlin et al., 2011). Studies on PwD care show that their carers can be confronted with significantly greater challenges (Adler, 2009; Gräßel, 1998) depending upon the symptoms and different stages of dementia (Koeppe et al., 2003).

HCI and Dementia

The HCI-based literature relating to PwD has grown over recent years and covers topics ranging from methodological approaches (Brankaert, 2016b; Brankaert et al., 2019; Hendriks et al., 2014; Lazar et al., 2017a; Morrissey et al., 2017b), music and artifact development (Benveniste et al., 2012; Lazar et al., 2017a; Morrissey et al., 2016a), exergames (Colombo et al., 2012; Unbehaun et al., 2018a, 2018c), and the use of art and design processes focused on reciprocity (Kenning, 2018). These topics emphasize using (creative) engagement as a way to articulate personality, with technology cast in a supporting role. This has further been illustrated design-led inquiries which have shown the importance of foregrounding personhood through designed artefacts, opening up space for emotional connection (Wallace et al., 2012). This design work takes into account shifts in personhood by both PwD, family members, and carers (Wallace et al., 2013b). Hodge et al. [2019] have adopted a similar approach by designing personalized interactive media for PwD, but also incorporating the personhood of carers (Hodge et al., 2019). Many projects have also focused on enhancing or replacing the cognitive skills eroded over the course of a person’s dementia. Here, technology seeks to help PwD to connect with their environment. An example of such an intervention is "Ticket to Talk", which serves to facilitate the exchange of personal memories and inter-generational conversation (Welsh et al., 2018). ICT can also deliver experiences that are no longer attainable in the real world. VR environments offer a creative medium for comfortable and enriching experiences that can promote and improve the quality of life for PwD (Hodge et al., 2018). An important outcome of many of these interventions is that they have sought to involve PwD and other stakeholders in the design process (Brankaert, 2016b; Unbehaun et al., 2018a). For example, in a study by Foley et al. (2019), interactions with residents with dementia in a care-setting were also seen as “*opportunities for collaboration*”. They showed in their work that by using tangible objects “*moments of (mutual) recognition, and meaning co-creation were supported through anchoring collaborative actions and sense-making in the physical world”*. Participation and being involved in a conversation can also create a sense of belonging, with PwD being recognized for their basic needs and social contribution (Foley et al., 2019). Here, it was important for researchers to be deeply involved in the interventions so as to understand appropriation challenges in a real-world context. However, despite the highly principled ethos attached to these approaches, the interventions are typically short-lived and framed by project timelines.

Design, Engagement and Appropriation of ICT in Dementia

Studies have shown that physical training improves mental health, (Patricia Heyn et al., 2004) cognitive, (Colcombe and Kramer, 2003) and physical performance (Hauer et al., 2012) in dementia. A number of technologies, have been specifically designed to support the daily activities of PwD and their families (Martínez-Alcalá et al., 2016; Schorch et al., 2016). Pinto-Bruno et al. (2017) argue that ICT can promote social participation and provide support to maintain or rebuild social networks, which may further improve social well-being (Pinto-Bruno et al., 2017b). When it comes to the design and evaluation of technology for and with PwD, their individual resources and social circumstances matter (Slegers et al., 2013). Some PwD may have limited expressive ability, so relatives or carers may need to serve as intermediaries, itself very challenging. Furthermore, Mayer and Zach argued that technologies aiming to enhance quality of life for people with dementia requires a deep understanding of symptoms, problems and user needs, not only of PwD, but also their stakeholders. Therefore, Mayer and Zach suggested that traditional participatory methods are not sufficient when dealing with people with dementia and that user studies often only generate limited insights (Mayer and Zach, 2013a). Bouchard et al. [2012] recommend developing appropriate interaction mechanisms for cognitively impaired people (Bouchard et al., 2012) and, in the context of developing Serious Games, the design and exercises need to be adapted to the cognitive abilities of the target group (Robert et al., 2014a). To handle these requirements all stakeholders must be involved in the development process, including PwD themselves. When developing guidelines for cooperative design with PwD, Hendriks et al. [2013] found that heterogeneous pathways meant all contingencies could not be covered. More studies are needed to establish even the most basic requirements arising from dementia and technology design (Hendriks et al., 2014; Slegers et al., 2013). One thing is clear, dementia needs to be understood in a holistic way, not just as a set of medical symptoms. In particular, good levels of communication and understanding need to exist between users and designers (Lindsay et al., 2012c). Lindsay et al. [2012] suggest undertaking design-related activities with PwD in small groups and adopting a familiar and easy-going attitude. Trustful relations are critical (Lindsay et al., 2012c). Various theoretical approaches have informed our understanding of technology appropriation and adoption, including (DeSanctis and Poole, 1994) and [18]. Our understanding of appropriation is inspired by Wulf et als view that appropriating ICT is "*a network of activities that **users** perform in order to make a software [or IT artefact] `work` in the new work environment*" (Stevens et al., 2010; Wulf et al., 2011, 2015a, 2018). As existing individual and social practices evolve through the use of

ICT, new practices may arise which go beyond what was originally envisioned and intended (Pipek, 2005). Wulf et al. [2015] argue that "*the quality of IT design can only be determined by looking at the changes in social practices resulting from appropriation activities*. Therefore, we argue, social appropriation requires a multi-stakeholder perspective. Stowell et al. (2019) point out that "*little is known about how exergames should be designed to provide benefits to the specific population of Dementia caregivers, who have unique challenges and who can benefit from increased support for physical activity and social connectedness".* They particularly note that "*without investigating technological opportunities and limitations for Dementia caregivers risks the creation of health systems that are unusable for this population, which can further exacerbate the health disparities between caregiver and non-caregiver populations".* This underscores the need to understand how both PwD and caregivers make sense of technology and the role they can play in its (social) appropriation. Thus, there is a growing need for "*a more holistic approach to exergame design: one that addresses the multiple intersecting aspects of a caregiver's life"* (Stowell et al., 2019).

The Role of Caregivers in Social Appropriation of Technology

To integrate new technology into work-routines and organizations, various factors have to be considered. One of the most important is making sure that potential users understand what the new technology can be used for and how they can profit from its use. By attributing meaning to experiences (Louis, 1980) it is possible to analyze why users are acting in a certain way. This is relevant for care home organizations because, in the context of dementia care, it can be helpful to understand that several interpretations of technical artefacts and interfaces are possible. Apart from situational influences, we also have to consider the effect of mediators, who assist users in their interaction with a new technology. Clearly mediators have considerable influence on users, but it is difficult to measure or assess how the process might be optimally organized, especially as the process is also dependent on the technology and the setting (Bansler and Havn, 2006). As Holthe et al. (2017) have pointed out, assistive technologies "*for people with dementia have to be simple, easy to accept, be introduced at the "right time", and be adequately supported by family carers and [..] professional personnel.*" To incorporate assistive technologies into the daily lives of PwD and their caregivers, the technology has to be appropriately introduced, with repeated training, commitment and support because it *"may take quite some time for people with cognitive impairment, as well as for their caregivers"*. Holthe et al. came to the conclusion that there is a need for further studies focusing on both the interaction of PwD with technology and the experiences of caregivers (Holthe et al., 2018). Similar conclusions have been drawn by Yamashita et al., who have developed technologies explicitly for caregivers [2013], showing that manual tracking technologies for caregivers can improve both the coping practices of caregivers as well as the relation between caregivers and receivers (Yamashita et al., 2013, 2017). With regard to the successful incorporation of assistive technology into daily structures, Arntzen et al. have outlined the driving forces that are involved in this complex process. Of crucial importance is an evaluation of the (regular) use determined by the caregiver, who, at the end of the day, has the decision-making power. Arntzen et al. stress that the successful integration of technology is not up to the PwD alone. "*The use and experience of usefulness are highly dependent upon the extent to which the family carers engage, and whether they become interested in the AT and in its potential to support".* The decision to incorporate and use technology in everyday life is bound up with their social practices (Arntzen et al., 2016).

Research Gap and Questions

In sum, to motivate PwD to use technology in general, they need to be able to understand the purpose of the technology and require help in making sense of the functions provided. However, their mediators also need to be able to perceive the technology as valuable and how it will contribute to the care, health and well-being of the PwD. This process of social technology appropriation is ongoing and situational and needs to take into account the ongoing support of mediators as well. Inspection of the relevant literature reveals that there is significant work dealing with the design of (assistive) ICT for PwD and some work that focuses on supporting caregivers. However, there is a dearth of research that combines these perspectives and examines the role of relatives and professional caregivers in mediating and integrating technology on a regular basis into the daily life of PwD (Arntzen et al., 2016; D'Onofrio et al., 2017; Holthe et al., 2018; Steve Lauriks et al., 2007). This paper seeks to address the following research questions: (1) What processes are recognized by caregivers to play an important part in the social appropriation of technology? (2) How are systems socially appropriated and contextualized, i.e. what social factors and characteristics encourage a willingness on the part of caregivers to integrate systems into everyday life? The study presented here provides some answers to these questions by examining the impact of a system on the social environment of PwD and upon the role of relatives and professional caregivers in supporting their daily life. We therefore look at the appropriation and perception of the system by informal and formal caregivers over time, and deliver findings regarding the social appropriation of technology in the long-term use in dementia care. The nature of our research demands an explorative qualitative approach that promises detailed insights into the social contexts and daily lives of PwD and their caregivers. Our study constitutes a grounded approach that may help us better understand the processes and factors of technology appropriation in PwD. The following section describes our explorative research design.

Methods

The research we report on below is a continuation of previous work done on the development of and ICT-based suite of exercise games for fall prevention with older adults (Ogonowski et al., 2016b; Vaziri et al., 2016a) and exergames for PwD (Unbehaun et al., 2018a, 2018c, 2018e, 2018g). These studies focused specifically on evaluating and understanding their long-term use by and for PwD. They demonstrated not only the physical benefits but also that the system helped PwD to recapture certain aspects of their social life and daily activities, whilst relatives could regain leisure time. While the results were mostly positive, there were also negative aspects to using the system, such as malfunctions and detection issues with the camera, which were largely attributable to it being a prototype. Other negative experiences resulted from feeling pressured to perform well when using the system.

Study Design and Approach

Over two years the ICT-based system was designed, developed and continuously evaluated in real-world settings and re-designed based on the insights gained. Here, we concentrate on the evaluation study at the end of a 3-year research project. Over a period of 4 months, the study examined the interaction of 53 PwD and 25 of their caregivers with our system. This took place across different settings, including day-care centres, care-facilities and domestic households, and involved PwD and their formal and informal caregivers. The caregivers were asked to set up and use the system according to a daily training plan that was based on sport-scientific evidence. We wrote and handed out a manual on how to use the system and its games and introduced it to the participants in two general “on-boarding meetings” in their institutions or homes after the initial deployment. The purpose of this approach was to examine how PwD and their social ecosystem would use the system. This paper focuses on the outcomes of the main evaluation study that was conducted between November 2017 and August 2018 in three different cities in Germany.

Participants and Setting

Overall, we had 108 interested participants for our main evaluation study. 43 of them did not meet the inclusion criteria and 12 withdrew after the first talk about the study. A call for participation was made via the university's homepage, a local radio station and by a call in the local press. The recruitment process of PwD in their households and care-institutions for the evaluation study was more difficult than expected. It turned out that, especially in private households the social situation was temporally and emotionally so constrained, that contact without a mediator was not possible. Therefore, we worked together with a local care provider who helped us to get in touch. The study included 53 adults with early to mid-stage dementia (assessed by their medical doctor) aged between 53 and 94 (average = 78,8) and 25 professional caregivers and relatives (aged between 34 and 97; average 66,4). 87% of the caregivers were female. Approx. 48% of the participants were married, 29% widowed. 23 of the participants went to care facilities and most attended various sessions on a regular basis.

Most of the participants lived at home and were cared for by relatives. Approximately 65 percent have a low to medium need for care and 35 percent have a high to very high need for care. The inclusion criteria for the study were a diagnosed ICD 10-diagnosed dementia, early to moderate Alzheimer type or vascular dementia, need for care given and determined by Barthel-Index, participants are retired and able to get up from the chair independently and walk at least 6 m, consent by their physician and their own consent. Participants were excluded from the study if: (1) their dementia was beyond a moderate stage; (2) they had in-parallel chronic diseases such as cardiovascular illness, neurodegenerative diseases (MS, Parkinson) or cancer; and (3) their physical fitness was impaired such that they could not walk without assistance. Relatives were asked to self-report on the general condition, capabilities, and diseases of the participants. This was then confirmed by professional caregivers. Ethical approval for the study was given by the ethical board of <name> and <name>. It is worth mentioning that the different kinds of settings were subject to specific empirical investigation. One of these was the ambulatory care where the system was deployed and executed at people’s homes, and the other was the stationary care facilities and day-care centres where the PwD are guests for the day, returning home in the afternoon. All participants needed to have at least a TV with an HDMI port at their home, with a minimum of three meters space in front of it, so that they could use the system without risk of injury. No financial compensation was offered to the participants. For both health and personal reasons, the number of participants declined over time. In both settings, there was supervision and maintenance to help if technical problems occurred.

Data Collection and Analysis

A qualitative methodological approach was used. Assessments and interviews were carried out with participants, relatives and professional caregivers. During the initial assessment and the deployment of the system in the settings, various health, socio-demographic and care-relevant information as well as interviews about the care situation and everyday life were conducted. Overall, 69 interviews were conducted before and after the evaluation study with PwD and their caregivers. We focus here only on the qualitative data obtained. This data consisted of audio recordings of interviews and field notes collected during the interviews and observations, here we performed a top-down Thematic Analysis (TA) approach (Braun and Clarke, 2006) to focus on a detailed analysis of the existing data, following a series of established steps, including coding of the material, then a systematic revision of the coded segments, identification of code families and at last their relationships in the search for themes (Braun and Clarke, 2006; Gibson et al., 2015). We created and named themes as *Perception of Individual Impacts on PwD when using the System from a Caregivers´ Perspective, Relative and Caregiver Feedback on Use Behavior, and Advantages and Benefits for Caregivers.*

Coding differences were discussed and eliminated by adding codes, editing them or deleting them. We identified a number of empirical codes that were used to encode relevant data excerpts across the entire body of empirical data. In what follows, we report on aspects of the evaluation study that illustrate how the videogame-based system was perceived and integrated into the daily life and work routines of caregivers, the key factors and crucial moments that might have facilitated appropriation and, finally, the social and individual factors that encouraged interaction with the system in everyday life. To triangulate our data we adopted three strategies: (1) talking to relevant actors about the same topics at different times and in different levels of detail, (2) talking to different actors about similar topics, (3) discussing our findings within the project team, which included experts from the field of sports and nursing science, as well as experts from NGO´s. Due to the vulnerability of the project participants and sensitivity of the health data, all of the interviews and field notes were anonymized, encrypted and stored on a university platform that is not used for commercial purposes.

System Overview

The final system contained several technical components that are displayed in Figure 24. The components were organized around a TV. A mini-computer equipped with the system-software and game application that was developed with a Unity 3D Game Engine (C#) provided

20 videogames. The system was connected to an MS Kinect to detect the movements of the participant when interacting with the system (upper part of Figure 24).. A set of more than thirty levels was incorporated into each videogame, providing an opportunity to match the resources and interests of the participants. After playing the basic levels, the degree of difficulty increased automatically and more dual and cognitive tasks appeared in every game. The system was connected to a backend information platform to generate user profiles, visualisation of results, initiating training schedules and unlock level progression (left part of Figure 1). A PlayStation 3 Buzzer was used as a navigation tool and input device during the games (e.g. to choose an answer during a quiz). The game-system had three different core videogame elements: 1) movement games; 2) coordination and balance games; and 3) cognitive and creative activities (right part of Figure 24). The system was designed to be played in single player mode, meaning that only one person was detected. However, other people could observe the different games and perform the exercises if they wished, though their movements were not detected by the system itself (lower part of Figure 24).

Games, Training Plan and Progression

The physical training was divided into strength exercises and a measured performance assessment. The strength exercises focused on lower and upper limb muscles that are important during functional movements, walking, and recovering balance. They included knee extension, standing knee flexion, standing hip abduction, and toe raises. The four balance and coordination games focused on providing percipience, balance, reaction and aim tasks in a playful fashion. The creativity and cognition aspects of the videogames were developed together with professional caregivers and therapists who work with PwD on a daily basis, focusing on music and biographical content.

The training schedule was designed on the basis of 2 years project experience, covering different evidence-based interventions from various disciplines (sports- and movement gerontology and nursing science), but also according to recommendations from the interview partners and caregivers, who suggested implementing games with a focus on music, biography and creative activities that were already established in the care facilities We therefore recommended a weekly training effort of about 180 minutes, i.e. about 20 - 25 minutes daily. Within the training plan, coordinative, physical/cognitive and creative exercises are offered alternately. After or instead of the training plan, the free game mode can also be used (additionally).

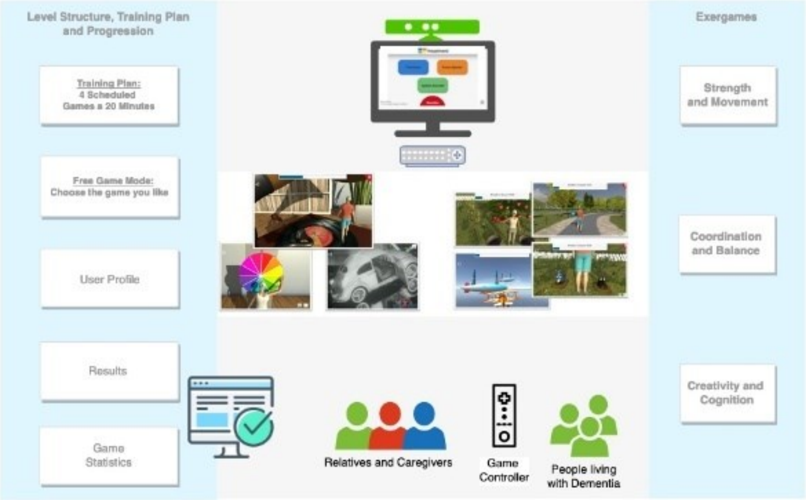

Figure 23: System Overview

The philosophy behind the game mechanics was to train the capabilities necessary for the execution of everyday activities (e.g. reaction, walking upstairs, hygiene). After a player achieved the minimum number of points required to complete a level, the level increased. The system was connected to a server from our care-software partner that hosted the training plans, administrated the player login and the transmission of training results. Both overall and detailed results, as well as the current level difficulty, could be monitored on a tablet by relatives and caregivers..

FINDINGS

Perception of Individual Impacts on PwD when using the System from a Caregivers´ Perspective

Improvements in Activity and Fitness

Informal and professional caregivers perceived an improvement in the physical and cognitive resources of PwD. A professional caregiver from a day-care center mentioned that, “*the individual participants increased their activity. One participant also knew exactly after two weeks what we want to do with him. Especially one participant improved her balance and could do the tasks without using a chair after a while*.” In another example, a professional caregiver described that a female participant, “*became faster in thinking, especially through the quiz games or by doing the arithmetic tasks. She learned a lot and I think that makes itself noticeable in everyday life.*” A relative in the domestic environment saw a *“significant improvement through the use of the arms and legs training. Also, these memory games, caused feelings of* *success."* A professional caregiver who is responsible for daily and social activities, who also moderated the session and motivated the participants explained that, "*so, with those permanent participants, it has advantages, you already notice reaction ability, body perception, and body feeling."* These effects are the outcomes of *"regular training [with the system]"* he added. A participant mentioned that the system and its variety *"stimulates both movement and the cognitive tasks".* The cognitive games in particular were rated positively. One participant reported, "*i have to honestly say that I really enjoyed answering questions like that when something was right. Sometimes you really had to think and use your head. Some were so casual and with some you had to really work hard and think, sometimes you could answer quickly and with some you thought "what was it like? To answer correctly and be happy about this inner self, that was especially fun for me."*

Stimulating Social Activities and Discussions

The creative games created a space for discussion and engagement. A social care worker working in a care-facility explained with regard to the historical clips that, "*when participants really started telling stories, even those who maybe otherwise said less, told us a lot about the past. You can watch it together and discuss it afterwards. That was always good to do in the group."* Another example of this was the music-based games. A professional caregiver stated that the group of participants she was responsible for, "*even ones, who were usually a little bit more reserved, enjoyed this game and sang along*." The group atmosphere was highlighted by participants. One participant mentioned that, *"yes, especially because you could also take part in something. Otherwise you can't do so much anymore. Especially in doing that in a group, yes, it's more stimulating." Another participant stated that playing in a group is, "yeah, more inspiring and encouraging".* Regarding whether anything more socially or emotionally-oriented had changed in the behavior of the participants, a professional caregiver said, "*yes, socially and emotionally, the participants were more open over time to come down with me and talk about the system. Our male participant talked a lot about it in his group living area [in the care facility] he always remembered and explained that system to other residents*". Regarding the creative games, one participant said that she "*enjoyed picking apples the most. It was just like back home. We also had apple trees and potatoes and I always had to help a lot at home. I also liked the quiz game. And I got along well with the buzzer*." Another professional caregiver added that 'funny features' in a game provoked positive emotional responses: the *"voice of the poor mole*" when being hit by a participant "*often resulted in huge laughter by the participants".*

Another interesting observation from a caregiver in a care home was that the games were a starting point for further discussions, even beyond the sessions and across different floors. In this regard a caregiver described the games played most and their impact, *"hit the moles, picking apples, flying propellers. And now in the last weeks a reaction test has been added to the favorites of the participants. With the lights, left-right test. Amazingly enough, they really enjoy it at the moment. Then there will be 'and how many milliseconds do you have?' 'Yes, under 600.' 'I had only managed 1000' Yeah, it's kind of a contest, I wouldn't have thought at first."*

Figure 24: Participant interacting with the System

Unexpected observations

A professional caregiver reported that one participant tried to manipulate a game to get to his favorite games sooner, *"it was not so important for him to execute the movement correctly, but the main thing was to finish it quickly in order to get to the nice things [Free Game Mode]. And then he liked to trick and cheat in the games while doing the official training plan. For example, he turned his arms so strangely during the arm movement's game that he was finished within a very short time and that's what it came down to in the end. So for one participant it was pretty easy, he always wanted to come to the free part quickly, play "hit the mole" quickly."* A professional caregiver mentioned another unexpected result, saying, , *"it was interesting to see, how it turned out that people who you thought weren't so physically fit anymore, actually can be active. You could draw them out of their shell. That some people who you might have thought were rather shy are still able to express and tell stories."* This was further confirmed by a professional caregiver, who was also responsible for a group with 5 or sometimes even more participants, who found it *“actually amazing with some, where you also say that the arms actually do not go quite as high as they try to get the arm there when picking apples. That's one of the ladies who really can't get her arms up and so she's got an iron will to finish the level or until the level is over, and if it's just the lower apples, but she was picking them. Every single one of them. She explained her behavior by the fact, that she had to do the same earlier at her home.”*

Relative and Caregiver Feedback on Use Behavior

Individual Use vs Group Use

On average, the caregivers and relatives reported that the system was used one to three times a week for a period of about half an hour to one hour. Mostly the system was used in the afternoon and the time of use depended on the relatives and professional caregivers. A day-care caregiver stated that they used it, “*in the afternoon where we have such a hole without activities, I liked using the system then to remove the boredom*”. It was reported that caregivers and relatives used the system differently and adapted it to their needs and daily schedules when possible. A professional caregiver said that they used it for both individual training activities and for group training, “*it went better if you did it all in a row, because then the people felt flattered. Ah there is something done with me alone, someone is there only for me. But the good thing in the group was that if someone else was there and the other two were observers, they also copied a lot. According to the motto, ‘oh, that's how it works’. So they learned a little from each other*.” The caregiver explained that two female participants felt better when they trained alone, *“they liked it better if you did it individually. They always asked extra questions and especially the two ladies, they always liked it better when they were alone.”*

Integration into daily life and workflows

When it comes to integration into work-structures a professional caregiver from a care facility explained that, because of her limited time capacities she would prefer to “*do that with all three of them together. Simply in terms of time, because if you did it with the people individually, it would have taken a lot more time. [...] And it went much faster if you did it together with the three of them.”* In response to a question regarding whether she would use it in the future, she said, *“I would use the physical games for daycare center participants who have more difficulties with their physical condition and [...] for those where you notice that the progresses of* *dementia increases quickly, I would put the emphasis on cognition."* Apart from seeing its possibilities as a tailored tool to foster activities with PwD, she said, *"I would also use it across the board, perhaps also really for the fitter ones who don't have dementia, simply because of the fun factor. We also had one with us, that wasn't actually a participant in the study who looked at it once. She has neither dementia, nor is she physically severely impaired. She also thought it was great, she would also use it directly. I think I would make that accessible for everyone then."*

The system seemed to be viewed as a useful instrument to encourage activity and social interaction. It also turned out that it was being integrated into other activities in care homes. A professional caregiver reported that, *"we're going to have a sports festival now, so I included that. This reaction test and 'hit the moles' as a competition then there's a medal for the participants and something like that. I'm curious if there will be more drive, if they want to play or not. Will we see that now the next weeks [after the project]."* Even movements from the games were implemented into other sports-related activities in one care-home. A professional caregiver said, "*the movements from 'hit the moles' are easy to integrate or the upper limb movements from the picking apples during other gymnastic activities."* The system was often reported to provide relief and serve as a useful addition to daily life for both types of caregivers. However, in some cases the professional caregivers said that they had, "*colleagues, who were less motivated [to use the system] then, that was a bit difficult".* This has to be set against the fact that, when personnel capacities were reached "*we just turned it on [free game] without following the training program, then it was easier, especially when we were partly understaffed for a while."*

Motivational aspects and empowered self-use by PwD

In interviews with care-workers from a day-care center another important point was raised. They mentioned how PwD could lack motivational drive: *"I think that if our participants had been more motivated, it would have been a relief for us. Because then you would have had time for the others to take care of them. But that is clearly due to [the dementia related development of] our participants. I believe that this [the system] is actually a relief".* Relatives had to motivate PwD to engage and empower them in using the system. One relative complained that, *"I must be the motivator, for many things."* Another relative mentioned, *"I had to motivate him again and again for the game."* Encouragement, then, was often needed. A relative explained that, *"I have to figure out how far I am able to motivate someone for something else."* Both kinds of caregivers, informal and professional said, *"we always had to switch on the system, otherwise it wasn't possible to train". "So, we really had to take over the role of the motivator."* Somewhat counterposed to these remarks, we observed that relatives and professional caregivers sometimes played together with the PwD or even alone. A relative explained that she sometimes played on her own, *"because my husband did something else, sometimes I played afterwards and sometimes I played alone in the evening, when my husband was doing something else. So it was very different."*

Advantages and Benefits for Caregivers

With regard to the integration of the system into daily life, a relative stated that having the system in the living room "*was a real help, because after her husband was not able to follow the instructions in the gym anymore, she trained together with him in their apartment."* When asked if the system was perceived as a relief in a care-home, a caregiver said, *"yes, for me it is, because I think it makes sense".* A professional caregiver felt that one advantage of the system was that, "*you don't have to think about what you offer your residents every day. What kind of leg/arm exercise do I do with people again today? That's actually a time saving aspect. You can offer your residents something different. Because you do a lot of the same thing here and this is also a contrast program*." She continued to explain by saying, *"it simply made people happy, and so did we. It's a good alternative to get in touch with people, too. To do something together with them. And the games were simple, well explained, people usually looked through quickly. And it's a good thing - both for the mind and for the body."* Integration into the activities of daily living was a crucial factor. A professional caregiver said that an advantage of the system was the *"daily training plan and that you have a fixed rhythm. The participants already knew some exercises and said 'Oh yes, now the hiking forest is coming again'. So the constant practice, I think that's of use. Physically as well as cognitively."* With regard to changes in daily routines and practices, another professional caregiver explained that, *"the system removed boredom, because we have such a hole in the afternoon activities and that was filled with the system, I liked that."* A relative highlighted the fact that system can be used with individual preferences and time constraints: *"you can do that individually as you feel like it."*

Both informal and professional caregivers mentioned that they saw the benefits of using the system to motivate PwD through its recurrent use. Relatives used the system because it "*makes* *exercises in general a bit more attractive [...] here at home. I can't motivate him to practice without the system. My husband also had a learning effect. At the beginning, he could not move to the side with his left leg. With the right it was possible, with the left to the front. Afterwards he managed to do it on his own in all four directions. Yes I noticed, it went better."* Another relative said that the system, *"makes everyday life more interesting for my mother. The system gives her a fixed task every day. It also seemed that it strengthened the movement and the cognitive abilities."* When asked if she would continue to use the system after the study ended, she replied *"yes, it is a good memory training and it gives it a structure to everyday life."* With regard to the PwD's well-being and activity before and after the study, a relative said that, *"it is better after the training. She now does the exercises even without the system. I think by using the system her mood is better."* The system was reported to motivate PwD to train their capabilities, especially when other regular daily training activities were not working anymore. Thus, a relative said: *"*I *tried to motivate my husband moving again and again. So when I give the impulse he does it too. But now I have to be careful that you stay and continue with the training, so that it doesn't somehow fall back too much, otherwise he wouldn't do that on its own."* Professional caregivers mentioned that they see "*advantages in the fact that it stays between coordination and movement. I was able to make that out with the group. We were able to spy. Someone who couldn't have been motivated to do anything at all, suddenly came out relaxed after a session."*

DISCUSSION

In the findings presented above we have seen how a videogame-based system fostered activity, create values and enable social interaction in the lives of people living with dementia. With regard to the research question, the system and its long-term interaction was reported to enrich and support the often complex, daily routines and challenges confronting relatives and professional caregivers, evidenced in frequency and intensity of use. Providing benefits for, and in, the daily lives of all involved stakeholders - what is discussed here as *social appropriation* - are the key processes recognized by caregivers. In this context, the willingness and motivation of caregivers to adopt and integrate the system into their everyday life is crucial. Furthermore, social factors such as the interplay between the stakeholders, PwD and the technical artefact facilitates this appropriation and the integration of the system into everyday life.

Individual Effects, Social Benefits and Impressions from Caregivers

Professional caregivers reported that they observed that group sessions enabled social interaction with others and gave PwD an opportunity to communicate with people with whom they are otherwise not regularly communicating. For instance, participants exchanged their experiences from the game sessions with other residents or caregivers during the day. Positive (social) sense-making and its effects were manifest in improved self-confidence, self-esteem and joy in life. These findings are in line with the existing literature, suggesting that the use of technology artefacts can improve activity, self-confidence and autonomy in PwD (Hodge et al., 2018, 2019; Steve Lauriks et al., 2007; Pinto-Bruno et al., 2017b; Wallace et al., 2012, 2013b; Welsh et al., 2018). Our analysis also revealed that games that focus on fun and music are especially well received by PwD and that the music-based exergame was mentioned by caregivers to trigger and evoke memories (Benveniste et al., 2012; Morrissey et al., 2016a). With respect to caregivers, our results suggest that the use of the system by PwD delivers positive effects for them. This is reflected in a number of the observations and quotes, implying that the improved well-being of the PwD facilitated the daily care routines of caregivers and relatives, for instance through an increased willingness to cooperate. Additionally, just one professional caregiver could introduce and explain how to use the system to three or four PwD at a time. This turned out to be a considerable time saver as the PwD were then occupied in a meaningful activity, so other caregivers could allocate their time elsewhere. These findings illustrate that the system and exergames may relieve informal and professional caregivers from aspects of their daily labours (Schulz and Martire, 2004). This also seemed to be true in terms of the social interactions and experiences that were facilitated in group-based training sessions. Communication and conversation among PwD and caregivers was reported to be easier and the system itself became a topic for conversations during and after the session by initiating *"social connectedness*" (Stowell et al., 2019). PwD continued to discuss their experiences with the system with each other. We therefore concur with the findings of Foley et al. that ICT-based interaction can foster collaborative action and create a sense of belonging through social participation (Foley et al., 2019). Furthermore, the professional caregivers noticed and reported improvements in cognition (thinking, memory and learning) and motoric skills (reaction ability, body perception, body feeling) (Brankaert, 2016b; Brankaert et al., 2019; Colombo et al., 2012; Hodge et al., 2018; Unbehaun et al., 2018b, 2018g), thus, supporting the studies that suggested that physical training can improve mental health (Patricia Heyn et al., 2004) and cognitive (Colcombe and Kramer, 2003) and physical performance (Hauer et al., 2012) in dementia. Professional caregivers reported that the system and its features was valuable in addressing and increasing socio-relational aspects in care-homes, partly providing sources of relief through time saving and creating enriched and tailored activities beyond the study participants. Combining these and the abovementioned aspects, a successful integration in care settings was fostered by considering the practical, emotional and relational aspects, noted as key requirements by Arntzen et al. (2016).

Long-term Integration, Social Appropriation and Sustainability

Our results illustrate that the adoption and integration of this kind of system depends decisively on the willingness and motivation of relatives and professional caregivers. Without meaningful effects (physical, cognitive and social) in the everyday life of PwD and added value for the relatives and professional caregivers, successful integration and (social) appropriation into everyday life and the living environment would not have been possible. In households, relatives used the system to make physical activity more attractive to the PwD, confirming one key requirement from Holthe et al. that successful technology integration for PwD needs to be *“adequately supported by family carers and [..] professional personnel”* (Holthe et al., 2018). Indeed, relatives reported that PwD were attracted to the system and played the games by themselves after their relatives had started the games for them. (Wulf et al., 2015a). This allowed more flexibility for relatives to concern themselves with other matters such as other household activities or maintaining their own social relationships by inviting friends over. Also, relatives perceived the system as supplying a daily structure for PwD. Individual and social practices therefore evolved over time through a multi-stakeholder network of social activities and the use of the system associated with it (Pipek, 2005). In this context, our findings are in line with Arntzen et al. (2016) that successful integration of technology is not up to PwD alone. The decision to incorporate and use technology in everyday life is bound up with their social practices (Arntzen et al., 2016). To sum up, the study findings illustrate specific advantages for relevant stakeholders initiated by the system within the social environment of PwD. In this respect, the system was observed to break down barriers and facilitate social connections for all parties. We argue that these effects are fundamental to the successful integration of technologies in the complex environment of dementia care. The results indicate that a successful and sustainable implementation in the multi-faceted and challenging everyday life of PwD and their social care network depends on many individual elements and a great many social factors. Appropriating and integrating technology is a very complex process that is influenced by more than the characteristics of the new technology, Thus a multidimensional, social process is implicated (Wulf et al., 2015a).

Apart from the benefits of the system for PwD, the findings suggest that relatives and professional caregivers as mediators of the technology were crucial factors in its integration. Informal and professional caregivers developed (sometimes unexpected) practices over time which empowered and motivated the participants to interact with and play the games (Wulf et al., 2015a). The use of the system was reported to foster activity, initiate positive emotions and provide meaningful interactional quality with other participants and caregivers. The social appropriation of technology and mediation are key to this success. A one-sided focus on technology with PwD limits the possible spectrum of solutions. As Arntzen et al. suggest (2016), *"The use and experience of usefulness are highly dependent upon the extent to which the family carers engage, and whether they become interested in the Assistive Technology and in its potential to support"*. The decision to incorporate and use technology is therefore situated in the particular reasoning of parties across the social actors about everyday life and their social practices.

The work presented here leads us to the following conclusions (consistent with (Mayer and Zach, 2013a)). Designs should aim at: 1) creating a familiar and emotive design that can remind participants of the past while making them feel comfortable; 2) ensuring minimum complexity so that the tasks do not overwhelm them; 3) making a good first impression so you are more likely to be accepted and the participants are more willing to participate; 4) providing positive feedback from the system that puts participants at ease and makes them feel they are proceeding correctly; 5) keeping instructions and learning requirements as simple and short as possible and open to being continually repeated; 6) involving relatives and caregivers in the operation of the system; and 7) keeping the visual design simple and rich in contrast for easy recognition.

Technical Drawbacks, Limitations and Lessons Learned

We have hitherto known little about the degree to which activities are sustained after a given project period is over. Although exergame use has clear potential benefits, there may also be challenges and unintended impacts on users or their families, and the ethical issues involved should be carefully considered ("Implementing-Assistive-Technology-in-Dementia-Care.pdf," n.d.). The social appropriation of ICT, particularly in such sensitive environments, and the continuous support for meaningful activities for PwD and their caregivers implicates trustful relations such as engagement, empathy and trustful communication across a number of dimensions. Existing literature has pointed to the need for engaging and building trust in long term research and consideration of the post-research phase, when technology is more embedded in everyday life is equally necessary as well (Meurer et al., 2018). So there is a need for a design and dementia oriented approach that provides evidence concerning the sustainability of interventions (Kenigsberg et al., 2019; Meiland et al., 2017). We argue that we have gone some way towards providing this evidence.

Nevertheless some limitations need to be considered, The interviews with PwD after the study presented a particular challenge. Due to the time sequence, the interviews were conducted shortly after the main study was completed, together with the removal of the system. It turned out that PwD had great difficulty remembering the experiences and interactions with the system. The researchers and participants also experienced frustrating moments due to technical errors, weak and unstable internet connections and issues with the movement detection by the camera. A professional caregiver summed up her experience by saying, *"This system could be a useful addition if the technology were to function smoothly. So, the game was fun for everyone. But it was like when the technique didn't work, it was very frustrating."* When technical issues occurred, it seemed to *"become difficult to keep the participants motivated"*. A further issue is the vexed issue of validity and reliability.

We are confident that our results are valid for the settings we examine. We worked with respondents over a relatively long period of time, and mutual trust was an important part of the work. While their observations about benefit are trustably valid for them but independent measures of a quantitative nature might provide additional value. The number of participants involved in this study was relatively small and it might be argued that it is therefore not necessarily representative of all care settings. In any event, our aim was to treat the stings we examine as perspicuous, meaning that they have promise for the examination of practices. We would suggest that this need and some of the related insights we have offered in our mainly qualitative study over the course of 4 months remain valid as examinations of practice. General reliability at this point of research on technology appropriation in PwD is fragile and long-term studies such as ours are scarce. Additional studies of this kind will, then, be valuable. One small further point that should be mentioned is that some of the participants in the study sadly had to withdraw before its completion due to illness. So, we need to recognize that, in this kind of context, one's set of study participants is necessarily fluid, which can have an impact upon the cohesiveness of one's findings.

Conclusion

The qualitative work presented in this paper, based on an evaluation study with 52 participants and 25 caregivers, has shown that our videogame-based systems fostered activity, initiated meaningful interactions, and enabled social impacts in the life of people living with dementia. The system was also reported to enrich and support the complex daily routines and challenges and even initiate time-saving effects, by using the system as an additional "tailored" tool for other residents to train their physical and cognitive resources and potentially alleviate boredom faced by relatives and professional caregivers. Relatives perceived the system as an instrument to set new incentives for training PwD and encouraging them to be active in domestic life. The findings also illustrate that relative's saw an added value in experiencing something new together with their loved ones and that the system served as something that could give a daily rhythm to the lives of PwD and support them by providing a daily structure. The findings confirmed the value of the work for the field of assistive technologies for and with people living with dementia, in the sense that videogame-based systems can facilitate physical or cognitive resources and encourage social interaction and support and partly relieve some of the pressures upon informal and professional caregivers in their daily interactions and work with PwD.

Finally, the results indicate that a successful and sustainable implementation in the everyday life of PwD and their social care network depends on many individual and social factors. It is a manifestly diverse and social process that can only succeed if the technology is embedded in the social context of PwD's everyday activities and care. The social environment of technology mediation and appropriation were found to be critical for success, with this opening up new possible arenas for technology-based solutions. Thus, the complex daily and institutional challenges involved in living with dementia cannot be solved through a technically oriented one-sided perspective. Instead, design solutions have to be developed in and with the social care-network. The potential of such systems, and of other assistive technologies, can only be uncovered if they are adapted to the individual changes in PwD and embedded in social practices. In this respect, we argue for a design and technology perspective in which technology in the dementia context leads to social innovations and thus contributes needs-based and practice-oriented solution models for professional and informal care..

MAJOR FINDINGS

The qualitative insights presented in this thesis illustrate that the exergame-based system can foster individual activity and social interaction - and not only in the lives of individuals living with dementia. In fact, in some cases, the system was also observed and reported to improve and support the often complex routines and daily challenges of the relatives and professional caregivers of PwD. In those cases, the provision of value, relief, joy, and benefits in the lives of the involved stakeholders was a key factor observed during the system evaluation. The individual and heterogeneous interaction of PwD with the system, the overall perception of the stakeholders, the role of the researchers, and the benefits, failures, and detriments of the technical artifact are presented in the following summarized findings.

Summary of findings

Individual Impacts and Social Benefits for People with Dementia

The results demonstrate that the use of the exergames system affected the individual and social lives of the PwD participants. In the conducted studies, social impacts occurred on an individual and community-based level during and after system use. Furthermore, increased physical activity and body language, in terms of straight and confident postures, for instance, were observed in PwD after they used the system. This observation aroused attention in the daycare centers, as the daycare guests who did not engage in the group sessions were encouraged to ask the other guests about the activities, which led to further conversations among them all. The group sessions thus facilitated social interaction, communication, and the establishment of new relationships. These findings suggest that the use of the system may improve aspects related to well-being, such as self-confidence and autonomy, and therefore affect the social lives of PwD. Caregivers reported that PwD seemed to improve their self-confidence by using the system and could then execute daily life activities more decisively and securely. Their ability to fulfill daily life activities, for instance, lifting objects from the ground and removing the garbage from the house, was reestablished after PwD used the system for an extended period. In this context, the results indicate that some participants in our study felt encouraged to and capable of completing household activities again and regaining their social responsibility.

These phenomena materialized in the case of a male participant, Mr. H, who often engaged in the daycare sessions in 2016 (see Chapter 5). While he played exergames in the daycare center regularly, he also wanted to train at home. When we discussed this idea with Mr.

H’s daughter, Silke, and asked whether dementia was restricting her father and whether he could train at home, she commented:

> *“It’s not that progressed at the moment. What is bad sometimes is that he doesn’t know the names of his grandchildren anymore and in certain situations can’t use them. There are also many things that were said just the day before that he’s forgetting.”*

After the system had been deployed in his home, he disclosed that he particularly loved to play the exergames with his grandchildren. Indeed, that was why he had wanted the equipment at home. He also stated that he found playing the games fun. It is important to note here that playing these games actively supported relationships that dementia might have otherwise challenged. However, Silke affirmed that her father was using the system “three times a week but also with the [grand]children for one and a half to two hours. He keeps a note of their respective high scores and compares his with the grandchildren’s. They battle each other, [and] it is going well.” Another significant outcome of Mr. H playing the games at home and with his grandchildren was that it freed up time for his daughter, his primary caregiver: “By the way, the game is also great for mothers. [I now have] hours of leisure time because the kids are playing together with Grandpa.” When we asked whether Mr. H was interested in any hobbies, Silke responded that

> *“the playing is his hobby at the moment. They [he and the grandchildren] have three fixed days, for which he’s thrilled every time. He knows exactly that these are the days he isn’t in daycare. I don’t play along anymore; I’d rather use the free time. So, the kids and Grandpa do it. In the meantime, he can also turn it [the system] on all by himself.”*

Concerning the daycare setting, we observed that daycare guests involved in the study were keen to face mutual experiences while using the system. The interviews with PwD and their caregivers suggested that the group sessions provided an atmosphere of cooperation and collaboration and created opportunities for group dynamics that increased individual enjoyment. These positive experiences seem to be important in fostering social participation and establishing or strengthening social relationships. In terms of the social impacts and benefits of exergames, the studies indicate that the sustainable use of such systems may generate positive effects, such as reduced dependence on general care activities and the improved well-being of PwD, that were observed and reported in previous chapters. In the ambulatory care setting, participants set individual goals for themselves, for instance, maintaining or improving their physical conditions by training with the system to participate in upcoming holiday activities, thereby assigning meaning to their use of the system. Overall, the findings regarding the ambulatory care setting suggest that the integration of the exergames can positively affect the existing relationships between PwD and their relatives and their everyday routines. Concerning the daycare setting, in our study, we found that moderated group sessions where PwD used the system evolved into a recurring activity that provided them with daily structure. This finding is reflected in several daycare events where PwD could hardly wait to participate in these weekly sessions—in fact, they waited in the entrance hall for the researchers to arrive. During the interviews, caregivers mentioned that PwD anticipated sessions outside the weekly schedule. Caregivers also reported that the regular participants at a daycare center waited in the group session room, even on unscheduled days.

Our studies have illustrated several significant results in this regard. As to the deployment of the exergame-based system, we found that for PwD, the system offered the core benefits around which it was conceived, fostering movement, improving self-reported physical fitness, and encouraging the use of memory and cognitive skills. In addition, the level-based difficulty system and the possibility of modifying the game structure according to different interests and individual physical and cognitive resources were deemed to be effective and motivating for the PwD. The diverse activities that were built into the overall suite of games such that PwD could move from more physically oriented to creative and biographical activities were considered especially beneficial. Nevertheless, the PwD themselves were aware of the social benefits that the system was delivering. They appreciated the quality of the experience in the daycare centers where they played the games as a group. Participation here was an event that they manifestly enjoyed, but it also allowed them to motivate one another with applause or encouraging comments, and we noted that they made active social arrangements around the games. We therefore assume that the weekly sessions and system were considered valuable to PwD and positively affected their daily life routines and experiences in the sense that the combination of the system and the sessions provided additional value to their lives. Participants in the daycare centers were observed to develop a certain group dynamic and a sense of interpersonal relationships when playing the games together, which strengthened their collaboration, as well as their motivation to participate in upcoming sessions. The social collaboration during the group sessions that the research team moderated was a major reason for participants to continue engaging in the sessions since these participants often encouraged and helped one another and a cooperative, respectful, and motivating atmosphere was thus created. Participants developed a strong sense of relationships in terms of "we do it as a group," as one participant stated. Passive participants who were not actively involved in a video game but observed the interaction of participants who actively played the game often applauded when a level or task was completed. Due to such positive experiences, group sessions became a recurrent event in the daycare centers, with participants regularly engaging with the exergames and building on the experience to explore a technology together while having fun.

Influence of the System on Private and Institutional Care

The several studies presented in this paper have suggested that our exergame-based system enabled social interaction and collaboration in the lives of individuals living with dementia. It was also reported that care facilities could profit from such a system in many ways in terms of a useful addition to current work structures, the provision of new experiences for their clientele, and the potential for institutions to develop their portfolios around the provision of such experiences.

By using a participatory design approach from the beginning of the project through the final prototype and evaluation study, we were able to integrate all actors and reveal the aspects of collaboration and social experiences that added to the existing body of knowledge, affirming the potential role that our system would have in the context of care for PwD. The entire process thus enabled us to consider and incorporate diverse needs, difficulties, and expectations in our design, leading to the development of a practice- and experience-based suite of exergames that fostered individual activity, initiated social interaction, and assisted PwD and their caregivers to face the daily challenges that they encounter in their social surroundings. Moreover, the findings illustrate how the system facilitated enhanced social interaction. Dementia can strain family interaction, and communication between family members can be diminished; however, the video games here provided foundations for interaction and allowed PwD to resurrect eroded social roles and responsibilities. In the ambulatory care setting, our system also promoted the reinforcement and reestablishment of relationships in households in some cases. In this context, the findings illustrate that the system sometimes supported mutual experiences between PwD and their family members, for instance, by regularly enabling cooperative gaming and exercising together with grandchildren. Here, we saw that the relatives of PwD began to develop an interest in the system and its games. In one case at a private home, a female participant was using the system with her granddaughter, which established a common activity that they engaged in together regularly. The participant confirmed, “We always played together”. Both individuals had a great deal of fun, which convinced the granddaughter to play more games with her grandmother in general. Observations and interviews during the LivingLab studies and evaluation stage indicated that such cooperative aspects helped PwD to regain or maintain social responsibilities and facilitated reintegration into familial structures and respective social roles. In our study, it seemed that the system encouraged and enabled PwD to reestablish some of their social and daily activities and thereby increase their self-confidence in this regard.

Additionally, the relatives and professional caregivers of PwD, as well as the external stakeholders, reported that the system combines the stimulation of physical and cognitive resources in PwD and facilitates and supports improvements in social experiences and collaboration across ambulatory care and daycare settings, not only for PwD but also for their relatives and professional caregivers. In some daycare centers, caregivers supervised the training sessions for security reasons when the system was first introduced; after the first few sessions, however, they ceased attending these sessions as they noticed that the participants were strongly engaged with the system and no longer needed guidance from their caregivers, which freed up time for caregivers and thus allowed them to invest more time in caring for the remaining daycare guests who did not participate in the sessions. In this context, some relatives and professional caregivers recommended using exergames as a permanent installation at home and in daycare centers.

Professional caregivers from care facilities explained that using the exergame-based system led to several concrete outcomes for the participants, such as improvements in their posture, self-awareness, and self-confidence. They also stated that the games were enriching the lives of the PwD by offering them a fun source of variety and direction. Much of this progress was attributed to the group dynamic that had evolved among the PwD, who benefited from encouraging one another to exercise. Furthermore, professional caregivers noted that the games had become an active topic of conversation in the daycare centers, which was in itself beneficial. Social cohesion is at its strongest when all involved have a shared topic to discuss. The system simultaneously facilitated more flexible time management and a reduced need for professional caregivers to supervise the participants when they were engaged in playing the games. Moreover, the results across the studies suggest that in some cases, the system also enriched the everyday challenges and complex routines that the relatives and professional caregivers of PwD often face.

Negative Experiences and Challenging Situations

Having described the benefits of using our exergame-based system for PwD and the related positive impacts on the social actors involved, we must now examine the negative aspects of what occurred during and after system interaction. An obvious source for negative experiences relates to technical issues and malfunctions. For instance, the concept of an avatar that mirrors the participants' movements sometimes proved too difficult or too abstract for the participants to understand. In some cases, the PwD and even their relatives considered the avatar an instructor and therefore expected it to demonstrate the tasks, which led to the incorrect execution of the games, sometimes resulting in significant frustration. For instance, one participant complained that "he [the avatar] doesn't do anything anymore." It was not always obvious to the participants that the avatar represented them and their movements; while most understood this concept from the beginning, a few of them struggled with it, and it had to be explained several times. For example, one participant stopped walking at first since she wanted to mirror the standing avatar, unaware that she could control its actions. Another participant was also unsure about the avatar in the beginning: "He does the same thing that I do, and [he] started marching like a soldier." The concept thus had to be clarified further in some sessions.

Guidance was often necessary to maintain the functioning of the game, especially with PwD who had an advanced stage of the disease. A significant factor concerning the system interaction was that our research model in an early stage of the project was not always ready to function as a free-standing system that PwD and their caregivers could turn on by themselves. Sometimes, of course, no amount of guidance can help. Regarding the music-based exergames, sometimes participants could not maintain the speed of faster songs and were unable to finish the game as they became exhausted halfway through the level. Similarly, some games demanded too much stamina (walking games) and therefore overwhelmed the participants in some cases. Additionally, while attempting to walk in place, most participants ended up slowly moving forward toward the TV. This action put them too close to the system; the Kinect camera would lose its tracking, disrupting the game, which often confused the participants and upset the flow of the game. When this happened, the active user was asked to step back so that the camera could re-detect them.

The variety and complexity of the system's technical issues and malfunctions, which were largely attributable to the system being a model, generally had a significant negative effect on the participants’ experience of using it. Some participants became impatient when the game mechanics performed incorrectly. One 72-year-old woman in a daycare center became notably confused, exclaiming, “I would like to put the apple in the basket, not stand around uselessly.” Furthermore, some participants were quite critical of other participants in the same group: “He [the active user] doesn’t understand this. You have to take down your arm. Take down your right arm. He [the active user] doesn’t understand this.” In the LivingLabs, it was commonly observed that participants who were watching someone else play the games would become rather impatient with the active user and convey as much by saying, for instance, “we told you to choose the other answer.” In some sessions, the participants told the researchers that they felt “comparable to a candidate in an exam due to all the other surrounding people,” which was onerous for them. Some participants mentioned that they felt excessive pressure, and some of them even began to associate using the system in a group setting with negative experiences.

In other instances, participants in households refused to use the system without the encouragement and guidance of members of the research team. One participant’s wife revealed the following:

> *“I’ve tried everything, and I cannot change it. (...) No one was there, and I tried to motivate him to use the system. After encouraging him several times to use the system, he screams at me or just leaves the room. He cannot be motivated to do anything. So, then, that does not work because he gets angry.”*

In fact, her husband seemed to be motivated to engage with the system only when the research team was around. We therefore had to remove the system after a short time since this conflict continued. The interviews conducted with PwD presented a particular challenge: we learned that PwD had great difficulty with remembering their interactions with the system—even when the interviews occurred one or two days after their last training sessions. The researchers and participants also experienced frustrating moments due to technical errors, as well as weak and unstable Internet connections. One professional caregiver summarized her experience as follows: “This system could be a useful addition if the technology were to function smoothly. So, the game was fun for everyone. But. . .when the system didn’t work, it was very frustrating.” When technical issues arose, it seemed to “become difficult to keep the participants motivated.” One point that should be mentioned here is that throughout the project, participants in the LivingLab studies and multicentered evaluation study sadly had to withdraw before the project’s completion due to illness and death.

DISCUSSION

Evolving Individual and Social Practices by Engaging with Exergames in Dementia Care

Our findings support other studies in that using the system benefited PwD by encouraging movement, improving their self-reported physical fitness, and inspiring their use of memory and cognitive skills (Legouverneur et al., 2011; McCallum & Boletsis, 2013; Padala et al., 2012a; Rosen et al., 2011; Weybright E., Dattilo J., Rusch F., 2010). In addition to producing those effects, the system—as the designers had hoped—offered PwD a source of fun, providing them with momentous positive experiences and making them feel good about themselves (Hodge et al., 2019; Steve Lauriks et al., 2007; Wallace et al., 2013b). Moreover, the PwD were aware of the social benefits that the system was delivering: participants reported their appreciation of the quality of their experiences in the daycare centers where they played the games as a group—a claim that the involved caregivers and stakeholders supported. Social participation and involvement in shared experiences were therefore events that the participants manifestly enjoyed, and these events allowed them to complete the recommended level of physical activity while motivating one another with applause or encouraging comments (Foley et al., 2019; Robert et al., 2014b; Stowell et al., 2019; Yamaguchi et al., 2011c).

Additionally, social dynamics occurred during and after system use. Some relatives and caregivers reported that PwD seemed to improve their self-confidence by using the system and were then able to perform daily life activities more securely by reestablishing such activities as lifting objects from the ground and removing the garbage from the house. In this context, the results across the different studies suggest that some PwD felt encouraged to and capable of completing household activities again and thus regained their sense of social responsibility after using the system for an extended time. These findings therefore also support other studies in that the use of exergames facilitates daily activities and may increase self-confidence and autonomy in PwD (D'Onofrio et al., 2017; Eisdorfer et al., 2003; Powell et al., 2008; Thyrian et al., 2017). In the LivingLab studies, caregivers reported that the body language of PwD improved while and after using the system, for instance, in terms of straight and confident postures. The positive atmosphere that was initiated during the moderated sessions at the day-care centers carried over into the afternoon and daily regular events, shaping and evolving the existing social practices and activities as Stevens et al. and Wulf et al. articulated (Stevens et al., 2010; Wulf et al., 2015a). This occurrence aroused the attention of other daycare guests who were not contributing to the study, encouraging them to ask those involved about the activities, which led to further conversations among them all. The group sessions thus facilitated social interaction, communication, and the establishment of new relationships. These findings and other studies suggest that the use of an exergames-based system may improve aspects related to well-being, including self-confidence and autonomy, and thereby affect the social lives of PwD (Melodie Boulay et al., 2011; Férnandez-Calvo B., Rodriguez-Pérez R., Contador I., Rubio-Santorum A., Ramos F., 2011; Hodge et al., 2018; Robert et al., 2014b; Wallace et al., 2013a; Weybright E., Dattilo J., Rusch F., 2010). As to the criticism concerning the integration of such technology among PwD, some participants mentioned in the LivingLab studies that they abhorred situations in which they felt coerced to act in front of others, and the comments of others could sometimes be critical rather than encouraging. Consistent with Karlsson et al. (E. Karlsson et al., 2011), we also recommend the use of informal or professional support to reconcile the issues that can arise with ICT-based systems so that the appropriation of this technology can be beneficial in the system's integration into daily life (Arntzen et al., 2016; Holthe et al., 2018; E. Karlsson et al., 2011). We thus strongly suggest that the social practices in interacting with the technology, its appropriation, and its impacts—not only on individual activity—must be considered in the development of ICT in dementia care. The daily and institutional challenges of living with dementia cannot be solved with a technically oriented one-sided user perspective; rather, design solutions must be developed in and with the social care networks.

Impacts of Meaningful Activities and Mutual Experiences Conveyed by Social Exergaming

The various findings illustrate that most PwD enjoyed using the system in the ambulatory care, daycare, and stationary care settings. Regarding the daycare setting, it was observed in the Living Lab studies that daycare guests involved in the study were all for mutual experiences while using the system. In the ambulatory care setting, assigning meaning to daily life activities seemed to be a significant factor for PwD when they were engaging with the system. In this context, participants set individual goals for themselves, for instance, maintaining or improving their physical conditions by training with the system to participate in upcoming holiday activities, thereby assigning meaning to their use of the system. Other studies reinforce that the meaningful use of ICT artifacts in daily living is key for the successful integration of such technology into the lives of older adults and PwD (D'Onofrio et al., 2017; Vaziri, 2018). Concerning the daycare setting, in our study, it was observed that the moderated group sessions where PwD used the system evolved into a recurring activity that provided them with daily structure and orientation. This finding is reflected in several daycare events where PwD could hardly wait for these weekly sessions. During the interviews, caregivers mentioned that PwD also anticipated sessions outside the weekly schedule. These sessions facilitated the daily care routines and practices of informal and professional caregivers, possibly relieving these caregivers from aspects of their regular labors (Arntzen et al., 2016; Schorch et al., 2016; Schulz & Martire, 2004; Schulz & Sherwood, 2008). We therefore believe that the weekly sessions and system were considered valuable to PwD and enhanced their daily life routines and experiences in the sense that the combination of the system and social sessions provided additional value to their lives.

The pleasant atmosphere of the sessions and encouragement of the researchers and other group members, especially the regulars, motivated and helped passive participants to test the games. A similar group effect was also observed in the daycare setting, where PwD with dominant characters tended to develop into group leaders, taking the lead in the games and attempting to motivate the other participants to perform as well as possible. This ambition had an infectious nature, as these group leaders generated a greater willingness to succeed among the others. What is notably interesting about this situation and the reported occasional embarrassment is that both demonstrate that, overall, the PwD were evincing a sense of social accountability, rather than remaining isolated with their concerns. This seemed to be a powerful force for keeping the PwD engaged and aware of the other individuals around them. It also provided an effective basis for expansive patterns of interaction. Additionally, what we observed and what several caregivers reported is that the combination of the moderated sessions, exergame interaction, and long-term involvement of the researcher became a locus for patterns of social engagement and social connectedness that extended far beyond the original project objective to train PwD in physical and cognitive activity. In other words, the system was observed as a "gate to engage"; it was socially meaningful and made PwD socially interactive within their social environments in ways that dementia is known to erode. The researchers certainly had a significant role in this occurrence. Caregivers employed at a daycare center who participated in the project for over two years highlighted the role of the research team and its related impact. One professional caregiver explained:

> *When you are coming, the reaction of our guests is, 'Ah! The university is here.' This effect is a relief for us. Our task here in the daycare [center] is to give the guests here a nice day. That is our intention and our work task, our life task. Give the guests a nice day, and then you are an integral part of it.*

This was confirmed by another caregiver, who mentioned, "I think it's always nice when you show up and conduct these sessions; even when you don't show up, the participants then pass the group room five times, checking [to see] whether someone is there."

In the evaluation study, caregivers had to command and use the system; however, in real-world scenarios without guidance, such prompt support cannot be guaranteed. While this, of course, could be true of most technological artifacts and prototypes, such systems could have a greater impact when designed for target groups with lower resilience. In that case, our results support the findings of Müller et al. (2010) that designers in this field must consider several aspects from the PwD and caregiver perspectives, the socio-technical perspective, and their interrelations. Technical infrastructures, evaluations, social surroundings, and system formats must also consider the various conditions and strategies of the distinct ways of managing the individual and social contexts of PwD and their caregiving networks more carefully (Müller et al., 2010). Especially by addressing socio-relational aspects and practice-based needs engagingly for an extended time, the appropriation and successful integration of the system into daily life and different care settings were facilitated. Furthermore, by considering the practical, emotional, and relational aspects that Arntzen et al. note as main requirements, as well as providing meaningful and tailored activities outside the scope of physical training incentives and increasing performance, social engagement, social connectedness, and accountability evolved (Arntzen et al., 2016).

The Role of Informal and Professional Caregivers in Mediating Technology

Concerning daily life integration, the findings illustrate that in some cases, when PwD used the system with their grandchildren, other relatives could continue leisure activities that had previously been set aside. Here, we saw that the grandchildren of PwD began to develop an interest in the system and its games. The system was therefore able to not only relieve the daily challenges of relatives but also initiate intergenerational aspects that supported PwD in readopting social roles and further facilitated communication and interaction across different generations, for instance, in the form of information or knowledge sharing (Eisdorfer et al., 2003; Holthe et al., 2018; Powell et al., 2008; Thyrian et al., 2017). These results and the existing literature suggest that exergames may address these intergenerational aspects and positively affect users' social lives (Pinto-Bruno et al., 2017b).

Regarding the ambulatory care setting, we learned that in some cases, the exergames promoted familial relationships. In this context, our findings suggest that the system facilitated mutual experiences between PwD and their family members, for instance, by regularly enabling cooperative gaming and exercising together with grandchildren. Observations and interviews indicate that such cooperative aspects helped PwD to regain or maintain social responsibilities and facilitated their reintegration into familiar structures and their respective social roles. In our study, the system seemed to encourage and enable PwD to reestablish some of their social and daily activities and thereby increase their self-confidence in this regard. Related literature includes similar findings, underlining the relevance of fostering mutual experiences between PwD and their relatives to produce positive effects in their everyday lives (Hannemann, 2006; Logsdon et al., 2007; McDermott et al., 2014; Sanders, 2005).

In terms of professional caregiving, caregivers supervised the training sessions at first for security reasons; after some time, however, they ceased attending these sessions as they noticed that the participants were strongly engaged with the system and no longer needed their guidance, which allowed caregivers to spend their time caring for the remaining daycare guests who did not participate in this session. Much of this progress was attributed to the social dynamics that had evolved between the participants, as well as the participants and their caregivers, with the spirit of collective encouragement. In this context, our findings are consistent with Arntzen et al.'s (2016), confirming that the successful integration of technology does not depend on PwD alone but must be "adequately supported by family carers and [..] professional personnel" (Holthe et al., 2018). In addition, professional caregivers reported that the games had become an active topic of conversation in the daycare centers, which was in itself beneficial. Indeed, social cohesion is at its strongest when everybody has a shared topic to discuss. The system simultaneously offered the professional caregivers certain process benefits as well, since it facilitated more flexible time management and a reduced need for professional caregivers to supervise the participants when they were engaged in playing the games.

Particular aspects of these findings have also been reported in other studies (Melodie Boulay et al., 2011; Férnandez-Calvo B., Rodriguez-Pérez R., Contador I., Rubio-Santorum A., Ramos F., 2011; Robert et al., 2014a; Weybright E., Dattilo J., Rusch F., 2010; Yamaguchi et al., 2011a); nevertheless, a comprehensive examination of these aspects in the context of a suite of exergames that has been specifically designed and evaluated for use with PwD and their caregivers has never been completed. Interviews with PwD and their caregivers reveal that the group training sessions provided participants with an atmosphere of cooperation and support and therefore created opportunities for group dynamics that increased their overall enjoyment of the system. As Stowell et al. expressed, these experiences seem to be important to maintaining social participation and establishing or strengthening social relationships (Stowell et al., 2019).

Social Connectedness and the Role of the Researcher

As Phinney et al. have noted, the above results illustrate that the effects of introducing the system that were observed in daycare included the forming of new social contacts and friendships and therefore a sense of connection during and even after the moderated sessions(Phinney et al., 2007). If one of the regular participants was missing from the workshops on a training day, the other regulars wanted to know why as, according to them, "something was missing." This strong group dynamic and the friendships that were formed in the workshops continued after the end of the sessions and even influenced the researchers as regular actors in the LivingLab. Altogether, the study findings demonstrate the specific advantages for relevant stakeholders that the system initiated within the social environments of PwD. In fact, the system was observed to destroy barriers and facilitate social connectedness for all involved (Stowell et al., 2019). The researchers' long-term cooperation and engagement in the field resulted in challenges, expectations, and new insights into dementia care. The continuous moderation and recurring process of these researchers enabled an undeniable familiarity between them, the participants, and the professional caregivers, which was expressed through a sense of belonging to the (social) environment in the sessions. This finding is reflected in several occasions where PwD could hardly wait for these weekly sessions. During the interviews, caregivers mentioned that the participants also anticipated sessions outside the weekly schedule. We hence assume that the moderated sessions and their social effects, the presence and role of the researchers, and the interaction with the system were valuable to PwD insofar as the combination of technology and recurring events enhanced and lent additional meaning to their everyday lives.

Due to the nature of the daycare training sessions, which involved three to six PwD, it might be expected that the deployment of the system was less successful in households on this score. However, we noted that the games had a similar effect of promoting intrafamily social interaction, even to the point of individual PwD being considered more fully functioning family members. In their study regarding the use of ICT-based reminder systems, Bejan et al. (2018) found that PwD enjoyed using technology more actively in group settings than by themselves. In contrast to the strength and training games, the creative and social games, which were fun and offered opportunities for social experiences, were crucial motivating factors for the PwD. In different settings (households and care facilities), the participants' focus shifted from the game to the entertaining and exciting group dynamics. During the group sessions in the daycare centers, the participants became active, cheered one another on, and interacted with one another. As noted, this effect was also observed to a lesser extent in the households, where the researchers did not guide users during individual sessions. In their study, Pinto-Bruno et al. (2017) examined the effects of ICT on the social health of PwD; they stated that in this context, ICT can promote social participation and support the development of social care networks. As mentioned in the previous section, the different group dynamics and formation of social care networks between the PwD and the researchers observed in the daycare setting led to increased social contact, which PwD perceived and hoped to retain.

A major outcome of the observations from and involvement in our research is the recognition that the games must be enacted in social environments, whether in daycare centers with peers or living rooms with relatives and friends. We must therefore surpass the original goal of the games to reflect on the social environments they will be used in and whether these environments can generate the desired level of social interaction and accountability. An appropriate social environment does not come out of the box with the technology; rather, it is incumbent upon other individuals to provide that environment, and this task often falls to caregivers. It is therefore unsurprising that our results illustrate that the use of the games did not deliver relief for the caregivers in the households, even though it did facilitate social engagement and positive experiences. Indeed, the PwD could not operate the system independently and needed their relatives' assistance to start and use the system, which means that these caregivers had to first become familiar with the system and then remain present for the games, with no time out. In the households, this situation was aggravated to varying degrees as some of the caregivers were also older adults and, according to their statements, had had little contact with ICT. Nevertheless, it was noted that during our deployment of the system, interpersonal relationships were established between the researchers, the participants, and their caregivers. The participants looked forward to the sessions—not only to playing the games but also to the contact with the researchers. Moreover, the caregivers reported that the PwD remembered the researchers and anticipated their return, which implies that intermittent visitors could be able to promote the kinds of social interaction that can remain socially significant beyond the confines of the games. Rather, it seems that interaction with the researchers provided a social dynamic that was beneficial for the PwD. While this occurrence may have resulted from the researchers being dissimilar to the various health professionals the PwD encountered on a routine basis and the researchers' willingness to engage with the PwD differently, our data can offer nothing more here than a recognition of the matter, which begs for further research.

Sustainability and Lessons Learned

Our findings confirm that an effective understanding of the highly individual needs of PwD and their relationships with their social surroundings requires all relevant stakeholders to be involved in developing and evaluating the impacts of ICT and especially the established video game–based systems. Across the ambulatory care, day-care, and stationary care contexts, we discovered that the collaboration and positive social experiences of the participants were supporting the appropriation of the video game–based system. One insight that came to the fore in all three settings was that the key factors that influence sustainable use, collaboration, and social interaction include how a system is designed and evaluated together with the relevant stakeholders—in this case, the relatives and professional caregivers of PwD and other involved parties—for an extended time. Using a participatory design approach in the LivingLab studies allowed us to reveal aspects of collaboration and social experiences, as well as gather meaningful insights from a practice-based perspective that added to the existing body of knowledge of health-related studies in the fields of HCI and CSCW, and affirmed the potential role of video game–based systems in the context of care for PwD. The participatory design process thus established a foundation for us to consider and incorporate diverse needs, difficulties, and expectations in our design, leading to the development of a practice- and experience-based suite of exergames that can initiate social collaboration and help PwD and their caregivers to face their daily challenges.

The sustainability of a research project is defined as the "infrastructure that remains after a research project ends" (Altman, 1995). However, we know little about the degree to which such activities are sustained when a given project period is over (Müller, 2014; Wulf et al., 2015; Meurer et al., 2018). In many cases, it is impossible to provide the technology and technical support to the same extent as before due to expired funding, for instance (Wulf et al., 2015; Meurer et al., 2018), which poses the risk that newly acquired practices will be disturbed or lost completely (Pipek & Wulf, 1999, 2009). The question as to which factors and strategies can contribute to ensuring the sustainability of a research project therefore arises. Earlier in the history of HCI, the aim was to create one “perfect” design for a set of specific use cases. Nevertheless, most systems are socially embedded and therefore underlie constant change (Wulf et al., 2015). Appropriation is considered a prerequisite for sustainability (Meurer et al., 2019). Ideally, the integration of the created IT artifacts should be observed and adapted in real-use environments in long-term studies (Wulf et al., 2015). Domains of aging and health care are often complex and cannot be reduced into a single-use case with a generic solution since they are highly dependent on the context of use (Wulf et al., 2019).

While exergame use has distinct potential benefits, it can also present challenges and have unintended impacts on users or their families, and the ethical issues involved should be considered carefully. As Wulf et al. indicated, “the ‘end of project’ decision-making can have a profound effect on the people we work with and – if honest with ourselves – we would accept that we have not always found a means to act in a fully responsible way.” (Wulf et al., 2015b). The appropriation of ICT, particularly in such sensitive environments as dementia care, and the continuous support of meaningful activities for PwD and their caregivers necessitates trustful relations. The existing literature highlights the need for engaging and building trust in long-term research; however, consideration of the post-research stage, when technology is more embedded in everyday life, is necessary as well (Wulf et al., 2015c). An approach that considers the sustainability of interventions in practice, even after research funding had ended, is therefore needed (Kenigsberg et al., 2019; Meiland et al., 2017; Wulf et al., 2015a).

Our findings suggest that the relatives and professional caregivers of PwD as mediators of the technology were crucial factors in its integration and appropriation. Over time, these relatives and professional caregivers developed (sometimes unexpected) practices that empowered and motivated the participants to interact with the games (Wulf et al., 2015a). The social appropriation of technology and mediation are both essential to this success. In fact, a one-sided focus on technology that addresses only the needs and resources of PwD limits the possible spectrum of solutions. As Arntzen et al. propose, “the use and experience of usefulness are highly dependent upon the extent to which the family caregivers engage and whether they become interested in the assistive technology and in its potential to support” (Arntzen et al., 2016). The decision to use technology therefore belongs to the social actors and depends on their particular reasoning concerning their lives and social practices. The results of the presented studies indicate that PwD and their caregivers are more likely to embrace such innovative technologies if the technologies address certain factors. These include flexibility, creativity, and adaptability (Brataas et al., 2010); clear ways in which they can be integrated into everyday routines; and a distinct value for all relevant stakeholders (Gonzalez-Palau et al., 2013; E. Karlsson et al., 2011; Rosenberg et al., 2012). These factors surpass the inter- and intrapersonal attitudes and practices of PwD and their caregivers and relate to how the care provided to PwD is embedded in a constellation of real-world necessities and limitations that the practical provision of care is continually obliged to recognize. When innovative technologies not only deliver positive experiences but also demonstrate a capacity to be embedded within or even improve existing care activities and practices, their value is more likely to be acknowledged.

Furthermore, the findings illustrate that the appropriation and integration of this kind of system also rely on the willingness and motivation of the relatives and professional caregivers of PwD. Without the regular meaningful (physical, cognitive, and social) effects for the PwD and added value for the relatives and professional caregivers, our system's successful (social) appropriation and integration into their living environments would not have been possible. In households, relatives reported that after some reassurance, PwD were attracted to the system and played the games by themselves after their relatives had started the games for them, which allowed their relatives to concern themselves with other matters, such as completing household activities or maintaining their social relationships. To design a device for sustainable use, designers are advised to involve the participants as codesigners from the onset of the project. Codesign activities can help to inform the participants of the opportunities that technology affords, as well as allow them to identify their needs and focus on the most fun and useful options for their lives. In addition, providing regular technical support during and after the project is crucial for sustainability. Especially for projects whose target group is older individuals, involving local authorities, care homes, and helping organizations has proven to be important (Meurer et al., 2018). As Müller et al. also reported, the observed effects of the evolution from the individual to collective use of technology through social activities, social bonding, and community building were considered a strong motivator for participating in the project (Müller et al., 2010; Wan, L., Müller, C., Wulf, V., Randall, D., 2014). We argue that these effects are fundamental to the successful integration of technologies in the complex environment of dementia care. Appropriating and integrating technology, particularly in dementia care, is a complicated process that depends on more than the characteristics of the new technology (Wulf et al., 2015a). Our results indicate that a successful and sustainable implementation in the challenging lives of PwD and their social care networks is a multidimensional social process that depends on a great deal of individual elements, including many social-emotional factors.

Limitations

One of the greatest challenges we encountered during this research was dementia and its highly individual course. It was impossible to predict how each participant would develop and react regarding the (long-term) system use and compared to the other (unknown) project participants. Two participants, for instance, were always involved in the daycare sessions but had to abandon daycare during the studies for health reasons and could not see the project through to its end. Other participants were occasionally and briefly absent. In terms of recruiting participants, it was difficult to contact PwD and their caregivers and even more difficult to convince them to be potential participants in the studies. We specifically needed participants diagnosed with early- to mid-stage dementia who could not only understand the activities but also interact with the system. Recruitment was made more difficult as PwD and their families necessarily endure a great deal of organizational and emotional turmoil after diagnosis. Dementia can also develop rapidly, and other age-related diseases can accelerate its progress. We could thus never be sure how our relationships with the participants and their caregivers might unfold. Designing and developing ICT, particularly in such sensitive environments as dementia care, and offering continuous support for meaningful activities for PwD and their caregivers necessitates trustful relations that involve genuine communication, engagement, and empathy across many dimensions (Hendriks et al., 2014; Lindsay et al., 2012c; Slegers et al., 2014). The existing literature stresses the need for engaging and building trust in long term research. Nevertheless, consideration of the post-research stage, when technology is more embedded in everyday life, is necessary as well (Meurer et al., 2018). The need for a design and dementia-oriented methodology that offers insights into the sustainability of interventions has thus arisen (Kenigsberg et al., 2019; Meiland et al., 2017). We argue that we have made some progress toward providing these elements; however, some limitations must be considered. Interviews with PwD alone or with their caregivers during their interaction with the system or after the studies presented a particular challenge. Due to the time sequence, the interviews were conducted shortly after the main study had ended, together with the removal of the system. The PwD had great difficulty remembering their interactions with the system. The researchers and participants also experienced frustrating moments due to technical errors, weak and unstable Internet connections, and issues with the camera's movement detection. A professional caregiver summarized her experience as follows: "This system could be a useful addition if the technology were to function smoothly. So, the game was fun for everyone. But it was like when the system didn't work, it was very frustrating."

However, various negative social experiences were also observed and reported during the studies, covering matters such as incorrect interaction with the system that led to moments of frustration, technical malfunctions, personal misapprehensions, and interpersonal frustrations in the group training sessions. Moreover, it must be considered that existing family issues or personal disputes that were observed between residents during the fieldwork will not be solved by deploying a video game–based system. Indeed, on some occasions, it actively aggravated them. When technical issues occurred, it seemed to "become difficult to keep the participants motivated." Additionally, it was generally difficult to obtain new ideas or design suggestions directly from the participants during the moderated sessions since they often withheld information during the interviews or claimed that they had no ideas. We therefore depended on participant observations, body language, and facial expressions and the information we acquired from the informal and professional caregivers to gain a sense of their assessment. During the games, the participants could be questioned more casually, and they would sometimes pass comments unprompted. However, no concrete answers were usually forthcoming when we asked them explicit questions. This result makes it difficult for researchers to find a balance between supporting PwD and empowering or influencing them (Lindsay et al., 2012a). During the observations, some insights could be gained by observing the PwD interacting with the system and others around them.

These limitations make it essential to involve informal and professional caregivers and other relevant stakeholders in the design process. While the interviews often produced little feedback, the use of a participatory design approach with a broader set of actors was more successful. Finally, technological artifacts, such as our exergame-based system, can also generate negative experiences. We mentioned before that the technical infrastructure built around the Microsoft Kinect was sensitive to different environmental conditions. Depending on these conditions, the system would not always function as intended, sometimes producing malfunctions and errors. Such events did not leave participants and their caregivers unaffected; instead, they led to much frustration and a negative overall experience of using the system.

CONCLUSION

It can be concluded here that—through the iterative steps of (1) exploring the individual and institutional needs of PwD and their various caregivers; (2) integrating and moderating our system in real-world settings for an extended time; and (3) including all relevant stakeholders in the design, development, and evaluation processes—the exergame-based system facilitated and promoted social experiences and collaborative interaction and maintained the independence and capabilities of PwD to some extent. On one hand, the findings confirm the value of our work for the field of assistive technologies for individuals living with dementia in the sense that the system fostered individual physical and cognitive activity, as formal and professional caregivers observed and reported during the LivingLab studies. On the other hand, the results illustrate that the system enabled and supported communication across the involved stakeholders and therefore provided a new scope for social contact, collaboration, and participation.

In some cases, the successful integration of the system into ambulatory care and daycare contexts led to various positive outcomes and improved the capacity of PwD to face the challenges of everyday life. Many of the participants who used the system at home seized the opportunity to connect and play games with their grandchildren and other relatives, which supported and strengthened the relationships that dementia often challenges. The collaborative and intergenerational interaction that the system motivated in several cases helped the PwD to recover social roles that had been eroded and facilitated communication across different generations. These cooperative aspects also seem to have helped the PwD involved in our study to regain or maintain social interactions and social responsibilities that were at risk of being undermined, aiding their reintegration into familial structures and their associated daily routines. Negative aspects of using the system simultaneously reveal some interesting challenges for the community regarding how to progress design in this area, notably concerning how PwD can be provided with the resources to understand the status of various facets of the system and its behavior.

In summary, the study findings illustrate the specific advantages for all relevant stakeholders that the system initiates within the social environments of PwD. In fact, the system was observed to destroy barriers and facilitate social connections for some participants. Furthermore, we argue that these effects are fundamental to successfully integrating technologies in the complex environment of dementia care. Our results also indicate that a successful and sustainable implementation in the challenging lives of PwD and their social care networks depends on several individual elements, including many social-emotional factors. Appropriating and integrating technology in different dementia care settings is a complex process that depends on more than the characteristics of the new technology; a multidimensional social process is therefore needed. It is a diverse social process that can succeed only if the technology is embedded in the social context of the everyday activities and care of PwD.

The social environments of technology mediation and appropriation were found to be critical for success, with these environments opening new possible arenas for technology-based solutions. The daily and institutional challenges of living with dementia thus cannot be solved with a technically oriented one-sided perspective; rather, design solutions must be developed in and with the social care networks. Especially by addressing socio-relational aspects and practice-based needs engagingly for an extended time, the appropriation and successful integration of our exergame-based system into daily life and different care settings were facilitated. In addition, by considering the practical, emotional, and relational aspects, as well as providing meaningful, and tailored activities outside the scope of physical training incentives and increasing performance, social engagement, social connectedness, and accountability evolved during the studies. The potential of such systems and other assistive technologies can be uncovered only if they are modified according to the individual changes observed in PwD and embedded in social practices. We therefore recommend a design and technological perspective in which technology in the dementia context produces social innovations and thus contributes to needs-based and practice-oriented solution models for informal and professional dementia care.

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