

Understanding the Difficulties of People with Dementia and Their Caretakers in Finland

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Abstract. The number of people with memory issues—and especially with dementia—is a growing challenge that raises both economic and psychological issues worldwide, and most healthcare systems currently emphasise pharmaceutical solutions to managing the everyday lives of dementia patients and their families. This study sought to determine the real issues experienced by people with dementia and their caretakers and the solutions they use. The study was carried out in Finland, and data was collected by online interviews due to the pandemic. The results showed that most elderly enjoyed music, stories and especially from interaction with other people. Many also suffered from too little physical activity, and some from sleeping disorders, leading to problematic behaviour. As the social meetings designed for the patients and their caretakers were arranged in different locations, there were also issues with getting there. The results were to be applied when building the non-pharmaceutical solution.

Keywords: Dementia Alzheimer's disease ICT technologies Elderly healthcare Caregiver Family caregivers Technological innovations Remote home care Personalised Serious game Gamification E-Health

1 Introduction

The purpose of this study was to find knowledge about the current problems and non-pharmaceutical solutions of people suffering from dementia, and of their caregivers in Finland. This research study was based on a request by a local association in Finland for seeking a solution to maintain relationships between dementia patients, their spouses and caretakers. Based on the findings, an innovative Serious Games package was to be created and the impact of using this artefact on dementia patients and their caretakers to be studied.

There are approximately 50 million people worldwide diagnosed with dementia and the number of dementia cases is increasing year by year all over the world. In 2050 there will be 152 million people impacted by dementia [1].

The main reasons for adopting non-pharmaceutical interventions are to minimize the drug–drug interactions and their side effects for using medicine on patients as well as overcoming limitations in pharmaceutical solutions for intervention [2].

In this study, we were looking for the most important issues which disturb the patient community's life. Moreover, we wanted to know what the current solutions are and which activities are organized for them in Finland. Based on the findings, an innovative serious games package will be created and the impact of using this artifact on dementia patients and their caretakers will be studied. The initiatives of this research project was

to find out the elements for building an artefact to be developed in the future. The aim in creating this artefact was to offer healthier and better care, and to enhance the quality of life.

2 Earlier Knowledge

2.1 Current challenges for the world, dementia patients and caretakers

Alzheimer's Disease International, a non-profit organisation, has estimated that the global costs of dementia in 2015 were US\$818 billion [3], and the average cost of taking care of a dementia patient is around 81% higher than patients with other conditions, such as heart disease, cancer or stroke [4,5]. These costs can be separated into direct costs, including in-patient treatment, institutional care, nursing homes, community care, specialist visits, family support organisations, medications and research and development institutes [6], and indirect costs to society for taking care of patients, including costs for family caretakers and unpaid research work. According to a study in Switzerland, direct costs represent 55.7% of the total costs of dementia and indirect costs represent 44% [6]. Another study found similar proportions of indirect costs for mild (42%) and severe (43%) dementia patients [7]. The indirect costs of supporting this community must therefore not be ignored [6,8].

The indirect costs of taking care of people with dementia can be categorized into two types: financial costs and mental costs. The changes of behaviour on dementia patients will request caregivers to spend more time and additional resources to prepare the physical and mental challenges which are caused by the illness [9]. To give better care to their life partner who had been diagnosed with dementia, family caretakers might need to reduce their working hours or even resign from their regular jobs [8,10,11,12]. The costs of informal family caregivers could be considered to equate to the salaries they would otherwise earn in the job market or the societal costs of paying a nurse or caretaker. The estimated amount of informal service offered weekly to a dementia patient at home is around 50 hours [6], and caretakers' quality of life and social activities might also be affected, rescheduled or reduced, depending on the level of dependency of the patients. These changes can be very challenging and cause depression problems in caretakers [13,14,15,16].

The enormous toll of dementia is not only financial, but also mental, both for those with dementia and their caretakers. Previous studies have shown that commonly experienced symptoms in this community include communication [17,18,19], emotional [20], behavioural [21,22,23], wandering [24,25,26,27] and comprehension [6,17,28,29,30] problems. Current medical treatments for dementia patients can slow the progress of dementia and improve mental health and behaviour, but pharmaceutical approaches are more focused on reducing symptoms than improving their quality of life.

Even though the lifespan of people with dementia is idiosyncratic, the average lifespan for people diagnosed with dementia is around 4 years—although some can live 20 years or more after being diagnosed [31]. As there is no medical cure and some patients' symptoms cannot be improved by pharmaceuticals [1], some patients and their caretakers might live with the symptoms for many years. Therefore, besides the financial and medical aspects, enhancing the quality of life of this group should be studied.

2.2 Importance of non-pharmaceutical therapies

Overuse of pharmaceutical treatment is said to create negative side effects on the patients and will reduce their joy of living [32]. Adopting non-pharmaceutical methods on people with dementia has potential to improve their quality of life and reduce their emotional and depression problems [33,34]. Instead of relying purely on drug therapy,

complimenting it with non-pharmaceutical treatment could reduce efficacy gaps and minimise the problems caused by maladaptive behaviour [16,34,35], thus increasing patients' self-confidence and decreasing their caretakers' burdens. Reducing the use of drugs can also lower the chance of side effects [36,37].

Non-pharmaceutical treatment is more effective in early-stage than in late-stage dementia patients. Although early-stage dementia patients will start to have difficulties with concentration or finding words or may experience changes in personality or behaviour, many can still take care of themselves independently and participate in social activities. Early-stage patients can therefore participate more and have more interaction using non-pharmaceutical treatment than patients at other stages [38].

Furthermore, the early stages of dementia can last for years. As non-pharmaceutical treatment can benefit patients by ameliorating symptoms and improving behaviour, it may also extend the length of the early stage. Annual per-person net costs for taking care of early-stage (mild), middle-stage (moderate) and late-stage (severe) dementia patients in Germany have been calculated to be approximately €15,000, €32,000 and €42,000, respectively [39]; as noted above, the indirect costs are only slightly less, and non-pharmaceutical treatment can be considered part of both [6,7,8]. Therefore, the contribution of non-pharmaceutical programmes is essential and irreplaceable. Since independence limitations, wandering problems, communication issues and inappropriate behaviour become more serious as the disease progresses from the mild stage to the severe stage, extending the length of each stage could contribute to reducing the overall financial burden on society and improving the patients'—and their caretakers'—quality of life. Therefore, the contribution of non-pharmaceutical programs for this community is essential and irreplaceable.

As a summary, one can conclude that considering the independence, wandering problem, communication skills and altering behaviour, changes in a patient are typically greater while the illness transforms from mild to a more severe stage. Extending the length of different stages in dementia has a potential contribution to reducing the overall financial burden of the illness for the whole society, and improving the quality of life for patients' and their caretakers.

2.3 Importance of personalization information in the therapies

Psychosocial interventions can have more beneficial effects than drugs, especially among those who suffer from the psycho-behavioural symptoms of dementia. Furthermore, while interacting with patients it is better for conversation experience if the topics are focused on their personal backgrounds and interests [1]. One of the three most important elements for developing efficient interventions in behavioural therapy is to include users' personal preferences [40]. The Health Foundation, an independent UK charity [51], contends that person-centred care is more efficient and can enhance service quality in patient treatment as it increases a patient's willingness to participate in medical care, which can reduce the use and costs of emergency hospital services [42].

Furthermore, "Tailored Activities Program" which considers patients' backgrounds and interests as one of its components, can improve dementia patients' behaviours, including 'shadowing, agitation, argumentation, and repetitive questioning' [43]. Thus, integrating personalised information and interests into a treatment programme can enhance its effectiveness [1,40,41,42].

Some dementia symptoms can be improved if the topics of discussions are related to personal preferences, as patients are more interested in speaking about topics related to their own life stories or memories [44]. When patients are more interested in participating in treatment, their self-confidence increases [44], improving their behaviour and health outcomes [41]. Topics with personalised content and preferences, such as pictures, music and videos, can stimulate the brain more than the same topics

with more general content [44]. Person-centred care services can thus offer a better quality of life to people with dementia [30].

2.4 How technologies benefit healthcare industry

Studies have shown that improving the quality of caring services is important to study both ‘care processes’ – which indicates the way a service is organised – and ‘staff interactions with patients as well as their families, referring to human interactions [42]. Therefore, using interactive mobile applications in dementia patients’ psychosocial treatments instead of only shifting its burden from caretakers to patients’ families and close friends, technology can allow more people to participate into the programs/activities, enhancing communication and connections between distant relatives and people with dementia [46].

Another important aspect is to consider how people with dementia can benefit from technology, as far as Serious Games are concerned. Instead of aiming for pure entertainment, a Serious Game is for slowing down the progress of the illness on a patient by maintaining their skills, abilities or/and behaviour by using this application. A study showed that the top five aspects of applying a Serious Game in health care are “education, exergaming, cognitive rehabilitation, psychology, and physical rehabilitation” [29]. Here, for this Serious Game authors are gamifying the personal memories of their participating patients, in a manner respectful to them. While the outcome of this application is targeted to be fun and catchy, it is aiming at becoming a research prototype to a therapeutic e-Health application for further research. In this research, the patient's personal multimedia content - in form of image, video and audio files – will be gamified into this application. Based on metadata analysis performed on the content level in application logic, the game engine is generating a unique, custom puzzle for the patients to play, containing their very own personalised memories.

2.5 Importance of this study in Finland

According to data reported by Statistics Finland, the proportion of people with dementia in Finland was the highest in the European Union (EU) in 2016 [42]. In 2017, 20% of stated causes of death for people over 65 in Finland were dementia and Alzheimer's disease [47], and, in 2018, 19% of deaths for people over 65 in Finland were caused by dementia—more than 10,000 people—and 33% of people aged over 85 died due to dementia and Alzheimer's disease [48].

The total number of people who died from dementia and Alzheimer's disease in Finland in 2016 was 9,200, which rose to 10,120 in 2018 [49,50]. Similarly, deaths caused by dementia and Alzheimer's disease increased 47.1% from 2008 to 2018 [51]. Therefore, the number of deaths from dementia and Alzheimer's disease in Finland has increased around 10% every two years and 50% over ten years. Moreover, dementia and Alzheimer's disease were the only causes of death that increased after 2008 [51].

The proportion of people aged 65 and over in the population is expected to rise from 19.9% in 2015 to 26% by 2030 and 29% by 2060 [52]. The trend in all European countries is for elderly people to want to be cared for at home [53], but resources and funding will probably not increase sufficiently to satisfy the service needs of seniors with dementia in Finland. The average total direct and indirect costs of caring for one dementia patient was around €36,000 euro per year in 2008 in Northern Europe [54], and, in the United States, the average total Medicare payment for a person with dementia over five years was almost twice that of a heart disease or cancer patient [55]. Thus, new or different methods or technologies that offer better and more cost effective services for caring for this group may relieve part of the financial burden on the country.

3 Research approach

This qualitative study used interviews to gather up-to-date information from current staff who were working for the Alzheimer's Association and the Alzheimer Society of Finland, to understand the present situation of dementia patients and their caretakers.

3.1 Qualitative research

Qualitative research is a useful method for collecting information on new topics or achieving a deeper understanding of a community, especially when the data is related to experiences, feelings and interactions within society. Responses can be unique and are more accurate when recorded verbally than categorically, as unique answers might not have been allowed for in existing assessments but are especially important when developing a new and innovative artefact [56]. Furthermore, individual interview is a usual way to collect data in health and social research study as it can prove the research group an in-deep knowledge in the area [57].

In qualitative studies, informants can be invited, such as by personal meetings, email contacts and public announcements. In general, qualitative research focuses on understanding phenomena instead of seeking representative samples, and it allows for more informants to be invited after the data collection has started [58].

3.2 Application of the research method

Participants

The criteria for choosing participants are relevant to their answers, and the informants in this research needed to have prior experience of caring for patients with dementia. In this study, authors discovered the contacts of potential respondents online from websites of two different memory illness supporting organisations in Finland: Alzheimer's Association and Alzheimer Society of Finland. Invitations were sent by email that asked recipients to answer the questions independently online.

Questionnaire

Questions for the interview were designed based on Stone's criteria: appropriate, intelligible, unambiguous, unbiased, omniscient, piloted and ethical [56]. The lengths, wordings, grammar and order of the questions were also important aspects of the design of the questionnaire [59, 60, 61].

Since the aim of this study was to understand the difficulties of people with dementia and their caretakers in Finland. Three main research questions were addressed: (1) What activities were arranged by the memory illness supporting organisations in Finland (2) What psychosocial challenges the people with dementia and their caretakers are facing? (3) Can activities reduce negative impacts by dementia symptoms in view of the respondents?

Interview's design and setup

Pilot tests were conducted during the development of the questionnaire and before starting the actual interviews. The objective for pilot tests in questionnaire design is to tap the experience and knowledge of people with similar interests and backgrounds to enhance the accuracy of the questions; to help determine what kinds of questions should be presented, the structure of the questionnaire and the format used; to avoid misinterpretation of the questions [61, 62]; and to ensure the interviewees will not experience difficulties or uncomfortable feelings when answering the questions [46]. Researchers can also get a better estimate of the time to complete the questionnaire to ensure that interviewees do not become exhausted [46]. Finally, pilot tests can uncover hidden problems, offering the researchers a chance to improve the instrument. When problems are found, the researchers must consider the necessity of modifying the instrument and how to do so [62, 63].

For this study, authors had invited a former occupational therapist to design the questionnaire before issuing it out to the targeted interviewees. In order to minimize and avoid uncomfortable feelings of the interviewees, all the questions in the questionnaire were cautiously selected and written. Furthermore, the length, words and sequence of questions were carefully considered [61]. Upon the readiness of the steps above, authors had invited two nurses to answer the questionnaire as a test. This was to ensure the interview could run smoothly, ensuring its quality and suitability for the study. After the test, some changes were made following the pilot, and questions were added to enhance the value of the research.

Methods

As the purpose of this study was to collect up-to-date information about current methods from professional caretakers, conducting a one-to-one interview was considered the most suitable method. The invitations for the interviews were sent by email, but, at the time of the study, a global pandemic was still ongoing, and no face-to-face interviews were possible. The interviews were therefore conducted online between the 3rd and 17th of April 2020, and analysis was conducted thereafter.

In consideration of cost and efficiency in creating the questionnaire and distributing it to targeted interviewees, the authors chose a readily available survey engine offered by Google. Results of the questionnaire were saved in Google's online storage and only authorised people were able to access and download the data.

After collection, the data was organised, summarised, categorised and reviewed. This study follows Braun and Clarke's [64] six-step framework for conducting thematic analysis: familiarisation with the data collected from the interviews; generating initial codes; categorising the data into potential themes; reviewing, defining and naming the themes; reporting the findings; and analysing them based on the initial research questions. The responses were transcribed and are summarised below.

4 Results

4.1 Profile of Participants

For this study, the authors sent invitations to around 70 contacts by email. In total, 16 participants completed the interview with full response data. All of the respondents had been working within activity-organising networks for dementia patients, either at the Alzheimer's Association or the Alzheimer Society of Finland. Six participants had worked with dementia patients for 20 or more years, two for 11–19 years and seven for 1–10 years. All of the participants had working experience with dementia patients, and only one did not specify the length of that experience.

The respondents described their educational and occupational histories to support the reliability and validity of their responses. To further assist the research, the interviewees also shared links and references online and traditional publications with more information on the topic of this research. Almost 70 percent (11 participants) of the respondents were interested in the progress of the research and further cooperation or participation in follow-up interviews and provided their email addresses for future correspondence.

4.2 Results

Out of 16 interviews with professionals of memory care, the following results were recorded in tabular and textual formats for each of the questions presented subchapters.

4.2.1 Please describe psychosocial problems faced by memory patients, their caretakers and family members?

In Table 1 below, psychological issues recognised by interviewees are presented. The generality of each psychosocial problem is identified by the total number of occurrences mentioned by memory care professionals in their interviews. Moreover, in order to recognise the significance of a single psychosocial problem for patients, their caretakers and family members, a percentage for weighted significance to each problem is calculated based on a number of occurrence proportional to its highest value. In comparison, the highest value of occurrence will always be assigned with 100% and other psychosocial issues a percentage relative to it.

Table 1. Psychosocial issues as faced by memory patients, their caretakers and family members

PSYCHOSOCIAL PROBLEMS		NUMBER OF OCCURRENCE	WEIGHTED SIGNIFICANCE
Emotional	Patient's depression / anxiety / emotional / mental problems	10	100 %
	Sleeping / resting / tiredness on patient	8	80 %
	Loss of friendship / social relationships / connections, feeling of loneliness / isolation from others	6	60 %
	Experienced shame on illness	5	50 %
	Sleeping / resting / tiredness on family member	3	30 %
Independence	Family member adapting to new roles a patient used to take care of before and feeling challenged by the new responsibilities	7	70 %
	Family members's depression / worry / sorrow / mental load over the patient	3	30 %
	Lack of initiativeness to function / operate as per situation	2	20 %
	Difficulty to join social events due to unavailability of suitable transportation / social support permitting to use it	1	10 %
Comprehension	Patient's worry over illness and loss of their skills/ability/accuracy to operate	2	20 %
	Incapability to receive up-to-date information from society, e.g. news and instructions provided only on the Internet instead of over traditional channels	1	10 %
	Problems due to a patient not being able to recognise family members or close relatives	1	10 %
Behavioural	Family members needing to adapt to changed behaviour or personality of a patient, e.g. aggressiveness	9	90 %

	Lack of diagnosis / care / information / on memory illness yielding to misinterpretation and misunderstanding by others	1	10 %
Wandering	Loss of direction / wandering outside a safe distance from caretakers/family	2	20 %
Communication	Incapability to follow conversations due to illness	1	10 %
Confusion	Illusions / Hallucinations	1	10 %

Furthermore, the same principle with the weighted significance and number of occurrence is applied to all the resulting Tables 2-6 in below.

4.2.2 What type of activities can improve or reduce psychosocial problems?

In Table 2 below, activities found as useful by specialists of dementia care for improving or reducing psychosocial problems are presented. Patients with diagnosed memory disorders require a variety of different activities to better cope with the illness. The content and arrangement of these activities are depending on the patient's level of illness and psychosocial challenges discovered.

Table 2. Activities found by respondents as useful for improving or reducing psychosocial problems

ACTIVITIES USEFUL FOR PSYCHOSOCIAL ISSUES		NUMBER OF OCCURRENCE	WEIGHTED SIGNIFICANCE
Hobbies and Exercises	Continuing the same hobbies and exercises as before the illness and as long as possible	10	100 %
Daily Routines	Support in maintaining the daily routines the same as before the illness and as long as possible	6	60 %
Rehabilitation	Activeness on chords and activities (preferably outdoors) at times awake to help issues with sleeplessness	6	60 %
	Listening to patients and caretakers for their worries	6	60 %
	Friendship companions for patients and their caretakers	4	40 %
	Discussions on pleasant memories as an exercise	4	40 %
	Support on independent completion of personal chords by patients, whereas possible	3	30 %
	Emphasis on arts, music and culture therapies for exercising the memory	3	30 %
	Being present to the patients and considering their needs individually	2	20 %
	Joint group activities mixed with memory patients and memory healthy people	2	20 %

	Tolerance to patient's memory issues and incapacibilities to remember	1	10 %
Transportation Support	Transportation services for patients and their caretakers	3	30 %
Care Substitution	Support on caretakers / relatives in management and duties of their own life	3	30 %
	Volunteer service for taking care of the patients as substitutes of their caretakers	2	20 %
Financial Support	Programs for financial support of patients and their caretakers	1	10 %

4.2.3 What type of activities do memory patients enjoy the most?

Concerning all the activities arranged for the memory patients, in the interviews the specialists of dementia care were queried about their popularity. The specialists were requested to estimate what type activities are most enjoyed by the memory patients. Patients with a diagnosed memory disorder require a variety of different activities for their better well-being. In the Table 3 below, the results on activities most popular among memory patients are presented, based on the observations by specialists.

Table 3. Activities enjoyed the most by memory patients as per the observations by specialists

ACTIVITIES MOST ENJOYED BY MEMORY PATIENTS		NUMBER OF OCCURRENCE	WEIGHTED SIGNIFICANCE
Activity Description	Listening to music	13	100,0 %
	Social gatherings / Getting to know new people / Conversations	12	92,3 %
	Puzzles, quizzes and games providing a sufficient level of challenge (not overly difficult) for memory rehabilitation and entertainment	11	84,6 %
	Outdoor exercising	8	61,5 %
	Memorising personal details / items, locations, events and history experienced	7	53,8 %
	Getting to exercise own dear hobby	7	53,8 %
	Singing together	6	46,2 %
	Indoor exercising	6	46,2 %
	Field trips out to learn new things	5	38,5 %
	Arts, painting and drawing	4	30,8 %
	Daily routines	3	23,1 %
	Activities personalised for the patient in question	1	7,7 %
	Variety of activities arranged for the patient	1	7,7 %

	Touches and sweeps	1	7,7 %
	Using a Memoera device for playing	1	7,7 %

4.2.4 What type of activities do caretakers and family members of memory patients enjoy the most?

Another very important aspect in treatment of memory patients are the caretakers and family members who occasionally are constituting of the same people. Occasionally, these people of highest importance as for the treatment are required to provide constant, round the clock support to a memory patient. Due to this, their both physical and mental capacities are challenged, which requires assistance from the society as well as memory support organisations involved in order to release them from stress, refresh them and not leave them in sole responsibility for treatments and care of a patient. In Table 4, based on the observations by the memory specialists, the activities enjoyed the most by caretakers and family members are listed.

Table 4. Activities most enjoyed by caretakers and family members of patients as per the specialists

ACTIVITIES MOST ENJOYED BY CARETAKERS AND FAMILY MEMBERS OF A PATIENT		NUMBER OF OCCURRENCE	WEIGHTED SIGNIFICANCE
Activity Description	Field trips / refreshing time out	10	100 %
	Social gatherings, interactions and conversations / confidential conversations	10	100 %
	Group time together with other patients and their caretakers / family members in peer groups	7	70 %
	Volunteer service for taking care of the patients as substitutes of their caretakers / family members and provide them with time for chords and refreshing hobbies of their own	5	50 %
	Outdooring / events in nature	4	40 %
	Visits / lectures by specialists	3	30 %
	Seasonal dinners together with fellow caretakers	1	10 %

4.2.5 Describe activities your organization is arranging for memory patients?

Until this point of the interviews, the specialists of memory care have thoroughly identified psychosocial issues experienced by the patients with their caretakers and family members, as well as the activities which are able to help their lives.

In order to respond to the social-economical requirements and demands the patients have by providing them with a respective service, the memory specialists are listing the activities currently served by their home organisations. A lack of correspondence of the service to the demand in the market would leave a gap for the Serious Game application to fill in and by this complete the pool of treatments required.

In Table 5 activities arranged for the memory patients by their supporting organisations are listed.

Table 5. Activities arranged for the memory patients by their supporting organisations

ACTIVITIES ARRANGED FOR THE MEMORY PATIENTS BY THEIR SUPPORTING ORGANISATIONS		NUMBER OF OCCURRENCE	WEIGHTED SIGNIFICANCE
Activity Description	Social gatherings and conversations with patients, their caretakers / family members, volunteers and visiting specialists (upon needs)	25	100 %
	Conversations in peer groups	18	72 %
	Memory rehearsals, exercises, puzzles, quizzes and games for performing individually / in groups	15	60 %
	Field trips	13	52 %
	Music as listened and sang	12	48 %
	Creation of supportive material and applications	11	44 %
	Outdoor exercising	10	40 %
	Indoor exercising	9	36 %
	Educational events / public lectures for information sharing	9	36 %
	Arts, handcrafts and poetry oriented events	8	32 %
	Seasonal celebration / events / dinners	6	24 %
	Visits by doctors of medicine specialised in memory issues	2	8 %
	Appointments with psychotherapists	2	8 %
	Friendship service by home visits / phone calls	2	8 %
	Visits by legal attorneys specialised in legal aid	1	4 %
	Models and practices for individual guidance	1	4 %

4.2.6 Which activities of yours make it possible for caretakers or family members to participate together with their memory patient?

Finding pleasure from learning, doing and enjoying the time together is one of the most crucial activities in coping together through the daily life.

Similarly, recognising gaps in service offering leaves a room and possibility for the Serious Game application to either support the existing activities or provide new possibilities for both the memory patient with one's caretaker and family members to learn and get entertained while helping to battle against the progress of the illness.

In Table 6, joint activities arranged for the memory patient with their caretakers and family members by the supporting organisations are listed.

Table 6. Joint activities arranged for the memory patient with their caretakers and family members by the supporting organisations

JOINT ACTIVITIES ARRANGED FOR MEMORY PATIENTS WITH BY THEIR CARETAKERS AND FAMILY MEMBERS BY SUPPORTING ORGANISATIONS		NUMBER OF OCCURRENCE	WEIGHTED SIGNIFICANCE
Activity Description	Social gatherings and conversations with patients, their caretakers / family members, volunteers and visiting specialists (upon needs)	10	100 %
	Memory rehearsals, exercises, puzzles, quizzes and games for performing individually / in groups	10	100 %
	Conversations in peer groups	6	60 %
	Music as listened and sang / Touch as a method of comfort	4	40 %
	Outdoor exercising	4	40 %
	Indoor exercising	4	40 %
	Field trips	3	30 %
	Arts, handcrafts and poetry oriented events	3	30 %
	Educational events / public lectures for information sharing	2	20 %
	Friendship service by home visits / phone calls	2	20 %
	Creation of supportive material and applications	1	10 %
	Seasonal celebration / events / dinners	1	10 %
	Visits by doctors of medicine specialised in memory issues	1	10 %
	Appointments with psychotherapist	1	10 %
	Visits by legal attorneys specialised in legal aid	1	10 %
	Models and practices for individual guidance	1	10 %

The informants explained that music and touch were important when dealing with patients, as was using several modes of interaction. When asked about the nature of the activities the caretakers enjoyed, they highlighted those that were performed among everyday tasks, sometimes offering example highlights.

Related to psychological problems in their daily work, the informants mentioned behaviour issues that they felt could be reduced by treating the patient individually and being present in her or his life. Interestingly, one respondent suggested that patients should be kept active when awake to avoid issues with sleeping during the daytime and then being awake at night.

Local organisations may offer peer groups, memory cafes and meetings for hobby crafts for the patients in which caretakers can also participate or take a break from caring. Some peer groups are arranged separately for patients, family members and other caretakers to allow confidence and discretion in discussions and to avoid hurting anybody's feelings. However, many patients and their caretakers face huge barriers to participating in available activities because they lack support, including a lack of public transport or a car.

Brain training was described in several responses. The greater the skills to manage daily tasks, the longer a family member can continue as the caretaker, and the most important objective in daily activities is encouraging the patients to be as independent as possible, such as by choosing and eating their own meals. In daily activities, tasks are broken down, and the patient receives encouragement and guidance, and brain activity is encouraged by urging patients to remember, do physical exercise, sing and engage in quizzes and word games.

5 Discussion

Dementia is an increasing problem globally that results in huge economic and human losses [3] and has prompted a lot of research as nations seek to reduce its burden [6,7,8]. The current study interviewed 16 respondents who reported their views and experiences of working with dementia patients and their caretakers. Most of the issues and challenges they reported were related to patients who suffered from behavioural changes that presented as problematic situations and feelings, but the respondents did not consider these to be the primary issue, but rather symptoms of the main disease, dementia, which needed to be managed with care.

The most important need was to reduce brain-related symptoms that prevented the patients from remembering or comprehending everyday moments. Efforts to reduce these symptoms included singing, telling stories, seeking memories and interacting in safe settings, which required time from the caretakers. Earlier studies have revealed how informal caretakers, such as family members, often need to reduce their working hours to spend more time with the person with dementia [8,10,11,12].

Interestingly, the informants mentioned that the different locations of the patients and the services, such as meetings and supportive activities, created challenges if transportation was not available. This is a significant issue that could be addressed with new services, but it is an encouraging finding as it offers a potential step forward for dementia patients.

Moreover, the interviews based on specialist opinions insighted the authors with on usefulness and entertainment the games, puzzles and quizzes provide for memory patients on daily basis. At current, as per the response data, there are indications on social demand and acceptance for this gaming to get digitalised, by an example of Memoera, which paths the way for further development of the Serious Game application. In this, specific carefulness in design of the user interaction, experience and interfaces is required to be paid attention to due to the acknowledge difficulty for memory patients in learning and adopting the use of new technologies.

6 Conclusions and limitation

This study had certain limitations. First, due to time constraints and available networks, only the people who worked at or with the Alzheimer's Association and the Alzheimer Society of Finland were involved. Other professionals, such as memory disorder therapists and nurses, who might also have valuable opinions, were not invited to participate. These missing participants might have had different opinions that could have expanded the information on this topic. Second, due to COVID-19 and social distancing recommendations, the interviews could only be conducted online, so some information, which might have been elicited in a face-to-face interview, could be missing. Finally, this study was focused on the Finnish context and therefore may not be generalisable to other cultural contexts.

The next phase of the research is a design science research project. The authors are in a process of developing a Serious Game application to reduce the symptoms of people with dementia and thus to enhance their quality of life in the future. As for further research and development of this as a prototyping game artefact and due to encouraging results on culture of gaming being strong within the memory training communities across the country, digitalisation of this gaming is considered as welcome.

Importantly, another supporting factor for continuation of research and development on the application is observed in popularity of sessions for memorising locations, events, personal history and past of the patient, in form of a guided exercise. In addition to personalised sessions, these exercises, similarly as gaming, are commonly taking place in collaborative, social formats together with their fellow patients and their caretakers. Thus, this setting and regular arrangement would welcome a Serious Game prototype to be further tested in a field trial type of setup in the patient communities. While one of the major psychosocial issues recognised is concerning the loss of friendship and social relationships due to illness, a field trial on the gamified application in social context of a group would give the research an interesting angle of assessment. Confirmation on whether a Serious Game of this type could be of assistance in preventing social isolation or not is yet remaining to be further researched and analysed.

Moreover, as a research approach further, more focus will be considered in directing the Serious Game application and its customised content to inclusion on past locations places and events personal to the patient. This has the potential to assist memory organisations in their constant requirement to develop content for their daily and weekly exercises with patients.

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