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mHEALTH-AD

Contract No. 2021-1-DE02-KA220-ADU-000028337

mHEALTH-AD

Training program for enhancing the adoption of mobile health technologies by persons with mild dementia

HANDBOOK MODULE 4: mHealth for communication and planning

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INDEX

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INTRODUCTION

Introduction to communication and planning issues of relevance to PWD

The continuous rise in the population diagnosed with memory impairment is concerning and dictates the need to take some action. In 2011, the EU Parliament recognized dementia as a "European priority," whereas the World Health Organization (WHO) identified dementia as a "public health priority" for 2017–2025. The WHO aims to design a future in which memory decline is eased and people with dementia can live well with respect and autonomy [4].

The progressive decline in aging is also associated with a progressive decline in cognitive abilities, such as memory, attention, and executive functions. Therefore, older people usually experience functional decline that can affect their quality of life, daily activities, and social interaction, as well as their social activities.

Memory deficits are one of the first signs as a person gets older. The older adult with an impairment in memory fails to recall recent occurrences and familiar persons, locations, and items. This may result in disorientation, irritation, social isolation, and health issues. Memory deficits can impair one's rational abilities. The older adult will encounter challenges in solving problems or making decisions and not understand abstract ideas like time and money. For those who have a severe decline in memory, this can make even routine tasks challenging, like grocery shopping and paying bills [5].

Moreover, older adults with memory difficulties start declining their communication abilities and language use. They might have difficulty putting their thoughts into words, following a conversation, and understanding what others say. This could cause feelings of loneliness in social situations and worry. As a result, they have trouble communicating and planning activities, remembering appointments, managing their medications, or keeping track of their finances and health, which has repercussions on their autonomy and keeping control of their lives[5].

Typical situations of conflicts-difficulties

Language skills change as people age and start to have memory deficits. Communication difficulties are one of the most common problems that will arise. The first signs are difficulties in expressing themselves and understanding others.

The most common difficulties that are related to communication are:

1. Loss of language abilities
2. Difficulties with word finding, specifically naming objects and people
3. Replacing a word with the wrong one or not finding a substitute at all
4. Confusion about family relationships
5. Describing an object rather than naming it
6. Repeating words, stories, or questions
7. Losing a train of thought

The progressive decline in communication can pose a barrier for caregivers and family members in understanding the older adults' thoughts, desires, and what they are trying to communicate. In some cases, the older adults' frustration about not being comprehended by others can lead to agitation and conflicts with their caregivers.

Another common challenge in communication and planning is the impairment of memory. Older adults with memory difficulties may have trouble remembering appointments, events, and important information, such as medications they must take. This can lead to conflicts with healthcare providers and family members.

Memory difficulties can also lead to issues remembering important tasks for everyday functions. Some examples of that are paying bills or preparing meals. This can create stress and conflict with caregivers and family members who may need additional responsibilities to ensure that the individual with dementia is cared for properly.

As dementia progresses, individuals may also experience personality, mood, and behavior changes, which can further complicate communication and planning. For example, individuals with dementia may become aggressive or agitated, making effective communication challenging.

Impact on quality of life

The decrease in these activities and the loss of social contact clearly impact the quality of life of the people affected, as it decreases their self-esteem and personal identity. Working on these aspects, supporting each person to develop and maintain significant activities safely and social and intimate relationships with friends and family promotes their well-being and self-esteem.

Older adults experience changes in their communication skills with the passing of time. Communication is very important for older adults, significantly affecting overall health and well-being. The role of communication is not only in one aspect of life, but it affects different aspects. Older adults feel socially isolated due to increased mobility and social interaction difficulties.

Moreover, they feel isolated and lonely, which leads to a decrease in their quality of life. The older adults , by keeping their communication active with close ones and the social network, can express their emotions and receive support. These strategies can help them reduce feelings of loneliness, isolation, and depression

Some other important reasons are:

1. Cognitive Function: Engaging in communication and social interaction can help older adults use their cognitive abilities.
2. Health care: It is essential for older adults to receive an appropriate health care plan and can understand it.
3. Safety: Good communication with caregivers, family members, and friends is essential for older adults' safety because they can ask for help in times of emergency and receive help.

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CONCEPT

TECHNOLOGY AND PWD

Introduction to mhealth solutions about communication and planning

People with mild dementia experience more and more communication difficulties and will search for the correct words when talking to someone or writing something. The continuous decrease of vocabulary will place the person with memory difficulties in situations where his/ her mind is blank, and their mind will try to substitute the missing word. Sometimes these alternative words are related words, but sometimes they are simply made-up words which to other people make no sense. At this stage we can observe that the older adults with memory problems begins to gesture more frequently.

At the same time, the older adults with memory problems experience a constant insecurity related to his day-to-day activities. He/ she is aware of missed appointments and forgotten tasks and feels a continuous preoccupation that more he/she has forgotten to do certain things.

Fortunately, there are technology options that can address both problems and diminish these challenges at this initial stage to some extent.

The typical requirements of a persons with dementia differ depending on the stage of disease and the personal situation (independent living / family involvement etc).
Frequent initial difficulties which are experienced are memory loss, mood swings, spatial and temporal confusion, difficulty in performing everyday tasks, problems finding things, decreased concentration, mild apathy, etc.
At this stage, it is common for affected persons to continue to reside in their usual home, where they have a better quality of life. In these cases, ICTs and electronic devices make it possible to maintain the safety of the older adults with memory problems in their own home and the ease of mind of family members. Other technologies such as telecare and GPS devices extend the duration the older adults with memory problems can stay in their home and allow the caregiver to monitor certain activities, so that rapid intervention can be provided in the event of a problem.

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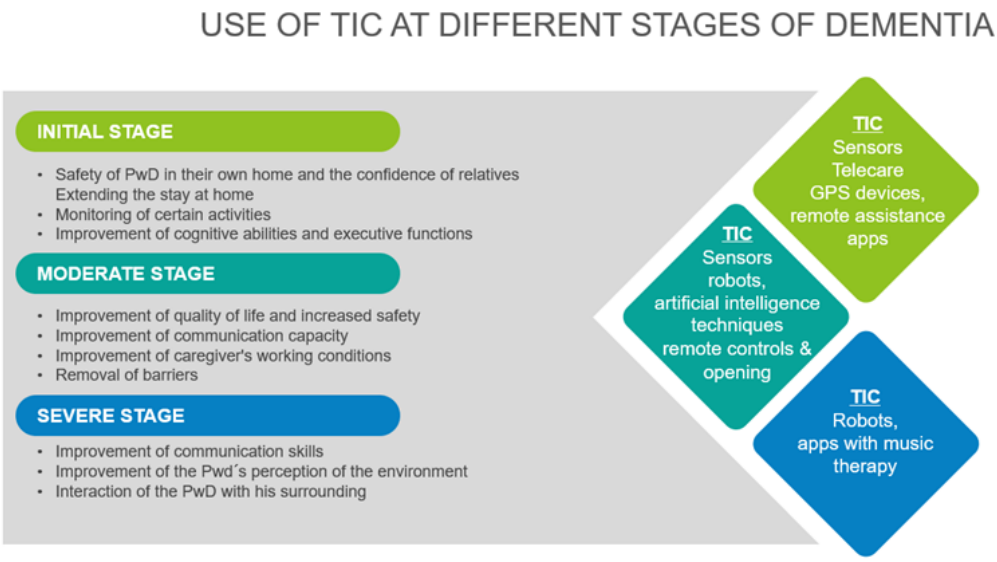

Mobile Health (mHealth) solutions are applications that are related to health. These are smartphone applications that offer services in order to improve the quality of life of older adults with memory problems and enhance their autonomy. Many applications are available for older adults with memory problems and their caregivers. The key component of their design is to offer more personalized care and cover the needs of people with dementia and their carers.
These solutions can take many forms, including mobile apps, wearable devices, and remote monitoring systems.

Mhealth solutions for memory difficulties can be used in various ways, such as providing reminders for medication and appointments, tracking and monitoring symptoms, providing educational resources and support, and facilitating social engagement and emotional support. In order to ensure that the care given to those with dementia is specifically suited to their needs and preferences, these solutions can also be personalized.

Overall, mhealth solutions can provide a range of benefits, such as improving self-management, reducing social isolation, and enhancing independence.

Benefits and barriers

MHealth applications target to improve health and the care is provided. There is an increasing number of applications that target older adults with memory problems. Examples of mhealth applications are to support older adults with memory difficulties in their daily activities, preserve their social interaction, maintain their cognitive abilities, tracking location, and monitoring health.

People with memory problems have been shown to benefit greatly from the use mHealth applications. We can observe a number of advantages.

The most important are:

1. Increasing Quality of Life: By giving older adults with memory problems the means to manage their health and stay in touch with loved ones. MHealth solutions can help them maintain their autonomy and improve their quality of life.
2. Support for Caregivers: By offering a pool of resources to access information and tools to assist in managing the care of their loved ones.
3. Cost-Effective aid: These solutions can also save money by lowering costs.

It is crucial to address the barriers and challenges to their adoption to ensure high-quality and user-friendly applications that meet each older adult's needs.

The most important are:

1. Digital illiteracy: Older adults have a lack of knowledge especially when there are memory problems, which makes less probable to access and use Technology
2. Privacy and Security Issues: The use of individual health data in mHealth solutions raises privacy and security issues.
3. Usability: Older adults with memory problems have difficulties in using and navigating in mhealth applications.

As a result, some barriers can be overcomed as long as mobile health devices fulfill certain criteria. For example, they have to be intuitive in order to avoid that the person with dementia memorize sequences. Also, they have to be designed in a way that is accessible for older adults with memory problems (less text, clear pictograms etc.)

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Empowerment in user-engagement

Empowerment is a key factor in user-engagement with mHealth solutions for older adults with memory problems in executing their daily activities. Empowerment refers to the process of giving older adults the ability to acquire knowledge, skills, and confidence in participating in the planning and management of their care. The empowerment to use mhealth applications leads older adults to adopt an active role in managing their health and makes them more likely to create a sense of control over their daily life.

To empower people with dementia, one needs to identify the specific needs of the older adult. This entails collaborating with them to develop the solution and taking their comments and recommendations into account.

Moreover, another important factor is providing education to older adults in order to ensure they use mHealth solutions effectively. Provide, also, support to people with dementia and help them to address any concerns or issues they may have.

This approach can result in improved quality of life for older adults and their caregivers.

Example of CIRCA (Computer Interactive Reminiscence and Conversation Aid) project:

CIRCA enhances speech production and helps to remember things from long ago in order to support persons with mild dementia to participate in group conversations.

CIRCA consists of a large database of images, videos, and music files belonging to different categories. This way, the people with dementia (PwD) does not repeat the same story over and over again and instead explores new topics. Family and friends or the PwD him/herself can add images, music or videos to the system. The implication of the PwD in the creation of the reminiscence space empowers the Pwd to take part in his/ her own support system as the system will support him/her especially at a later stage of dementia.

Improvement of self-management

The use of wearable technology can improve the self-management of a Pwd regarding the interaction with their monitor health indicators such as heart rate and blood sugar levels as well as those indicators associated with mental health distress. Many of these devices could transmit the retrieved data directly to healthcare professionals and therefore improve the information which the professional has at hand to diagnose. This way communication of health indicators is non-verbal but can be relied upon. The Pwd knows that his/her physician will receive the correct data, and this way the Pwd can still manage his/her health issues independently at the initial stage of dementia.

Enhancing self-management is important in the planning of dementia care.By encouraging older adults to take an active role in managing their health, they can improve their quality of life and promote better health outcomes. Some mhealth solutions that can enhance self-management in people with dementia in planning are reminders and prompts. Mhealth solutions can provide reminders to people with dementia in order to take their medication, attend appointments, and participate in activities that promote their well-being.

In addition, in the aspect of communication, it can help people with dementia acquire social support. Mhealth solutions can facilitate social support networks, connecting people with dementia with their caregivers, friends, and the community.

AVAILABLE MHEALTH TECHNOLOGIES

COMMUNICATION DEVICES

The relationship of people with dementia and technology devices and their aptitude to engage with the technology depends to a great deal on whether these persons have had contact with technologies before they experienced their first signs of dementia. Persons which have already used video conferencing before usually engage rapidly with this form of education and can use it although their dementia advances. On the other hand, for people which have never been in

contact with this type of technology, the digital world remains difficult or impossible to access after falling ill with dementia.

Assistive technologies are required to support personal communication and social interaction as people with mild dementia in particular are currently up against many challenges in everyday life e.g. when interacting with the health system or with public services.

When using such tools, verbal communication can be substituted by non-verbal, e.g. by replacing words by symbols, or even translating symbols into voice.

eHealth has the potential to empower citizens to better manage their health and disease, improve prevention, enable more accurate diagnosis and treatment and facilitate the communication between healthcare professionals and patients.

Outside of or alongside formal care, older people and their families are also turning to new and emerging technologies not only as a means of communication but also as a safeguard, for example, to alert their family to a fall.

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What is available?

There are many devices available for persons with dementia (PwD), which help them to stay in contact with their family, friends, and caregivers.

For example, there are commercially available telephones which are adjusted in some of their functions and designed to comply with the needs of a PwD. Special functions of these phones may be that they

- can be programmed with most frequent contacts of the person with dementia
- are designed with large buttons or pictograms or photos of the person they want to call

Video chat services like FaceTime and Skype are another great way to stay in touch with loved ones who are geographically distant.

Another aspect of communication support is the direct assistance with coherent speech, rather than the facilitation of a communication channel. An example for these technologies is the technique of Talking mats[1], which is available in the form of paper cards and a mat as well as a digital version. This concept allows a person with difficulties in speech to classify topics into three categories. The person is presented with different pictograms and can classify them on a digital mat in previous established categories. This exercise must be prepared beforehand and can help to identify the feelings of this person to certain topics as for example to identify actions with which he/she still considers himself independent as well as actions which he/she believes to be able to master by his/her own. Support functions like this one empower the person with difficulties of speech to take more control of his /her care situation.

Another example for speech support is the technology CIRCA (Computer Interactive Reminiscence and Conversation Aid), which “was developed to enhance speech production and recall from long-term memory, while minimizing the impact of working memory impairment” Projects have shown that CIRCA supports PWDs in group conversations. Similar to talking mats, CIRCA consists of a large database of images, videos, and music files belonging to six categories of which three are arbitrarily shown. This is done to avoid that the PwD iterates the same story repeatedly and instead explores new topics. Family and friends or the PwD can add images, music, or videos to the system to add individual categories which are of importance to them.

[1] https://www.talkingmats.com/about/our-resources/#social-care

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Voice-activated Dictionary tools/apps can support the Pwd to set reminders or to create a daily routine. However, they can also help them to communicate in a written form when it becomes difficult for the Pwd to read or write. The Pwd can use a voice to text function and dictate letters or instructions. This way the Pwd can still engage in communicate his/her own needs and can partake in planning activities.

The same applies to the use of Digital notepads and communication tools, which can be employed to help maintain the mind on a specific topic and collect information on this topic whenever it comes to mind.

There are certain apps that support interpersonal communication related to health parameters that enable patients to have direct contact and communication with a health professional. These apps may include diary logs so that the PwD can register any further information and send it to the health professional. Just like the wearables, these apps thus empower the Pwd to partake in his/her self-management.

The use of screen reading software on computers and smartphones enables the Pwd to read books, navigate the web, use a range of software applications, and to write letters, articles, and emails, although the writing and reading process itself already becomes difficult for the Pwd. It also offers the Pwd the option to not expose his/her condition to other people immediately as they can still receive instructions, appointment details or other messages in the written way, as the screen reading software reads it out loud for them.

Another option for communication support is the use of robots as they can be programmed to interact with the patient and give him company. A robot does not tire to repeat instructions or certain phrases as many times as necessary and does not transmit impatience or frustration which a human inevitably feels in this situation. In addition, each robot can be prepared to talk in a specific type of voice (female, male with local accent or not) and does not require any specific settings.

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A way for people to communicate when they no longer have the physical ability to use verbal speech or writing, is by augmentative and alternative communication devices (AAC). These devices can help a Pwd to vocalize thoughts or necessities by means of pictograms in a program that can talk depending on which pictures are activated.

Associated costs

The main basic costs for communication devices are the internet and phone line costs which are needed for most of the devices.

The cost of an adapted telephone may vary between 50-200€.

The cost of the online version of talking mats including an explanatory and personal online session (in English) is 360€

Cost of a conversational robot: 8000€

Cost of an animated pet: approximately 130€

Cost of AAC: AAC can be available in the form of free or low cost apps for the tablet or the mobile phone, or as specific communication support device. The price of specific devices can vary. One example may be the Pocket Go Talk 5 Level device, which can be purchased for 170€ and includes basic picture support for people with impaired communication skills.

https://www.speechpathologygraduateprograms.org/2017/11/top-10-aac-augmentative-and-alternative-communication-devices/

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PLANNING DEVICES

Memory deficits make it harder for the older adult to organize his daily activities and keep up with his routine. Another important aspect is medication management which is important for their health management and the quality of life of the caregivers. The older adult may have a medical condition like hypertension and may be hospitalized for non-compliance with the regimen.

The technological advancement in smart applications and devices is offering a lot of strategies and solutions that can help them manage their medication and reminders for their appointments.

What is available

There are many applications and devices that contribute to assisting older adults that have memory problems**.** Some of them are:

Voice reminders

Voice reminder devices allow users to produce personalized reminders. The voice reminder can be programmed to a specific time for the reminder to play.

Clocks

Clocks that can specifically display the time and help the older adult to be oriented in time. Also, some of them have the ability to set the alarm and reminders for appointments.

Applications and Smartphone

Smartphone applications like Calendars can be set to remind appointments or help organize their daily activities.

Medication reminders

There are automated pill dispensers that can easily be programmed to beep, flashlights, or make a signal when it’s time for medication.

An application that can be installed into the smartphone and manage the medication, provide reminders and the doses of the medication.

Water Reminders

Applications can be installed into smartphones to remind the older adult to drink water, how many glasses of water they need, and manage their water intake.

Associated costs

Applications

Most of the applications are free to install on a smartphone or tablet. You will need an internet connection, a smartphone or tablet, and sometimes an email address. Sometimes, there is a subscription fee, depending on the application.

Smartwatches

There are many brands in this category. The prices range from 40 Euros to 200 Euros.

Smart Speakers

There are various brands and prices range from 40 Euros to 150 Euros.

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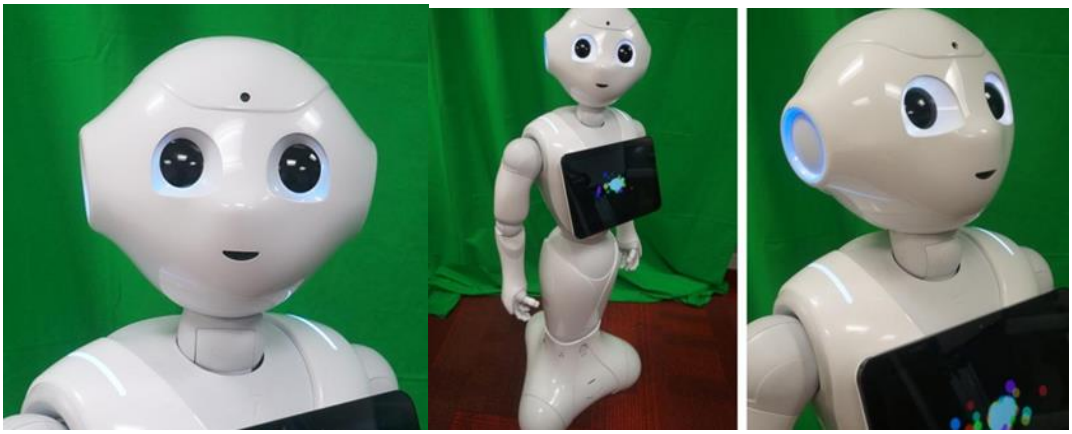
VISUAL EXAMPLES

Examples for communication robots:

Pepper



https://www.alzheimers.org.uk/blog/how-can-robots-support-people-dementia

EVA Robot

https://es.oceanomedicina.com/nota/e-health-es/eva-el-robot-que-acompana-a-pacientes-geriatricos-con-demencia/

Examples of animated pets:

https://dailycaring.com/robotic-cat-brings-joy-to-seniors-with-dementia/

Example of AAC:

https://www.researchgate.net/figure/Some-Augmentative-and-Alternative-Communication-devices_fig15_266558490

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Examples for Planning:

1. **AP@LZ application**

https://www.researchgate.net/figure/Homepage-of-APLZ-version-1_fig1_313799832

2. **Smartwatches**

Source: Pixabay

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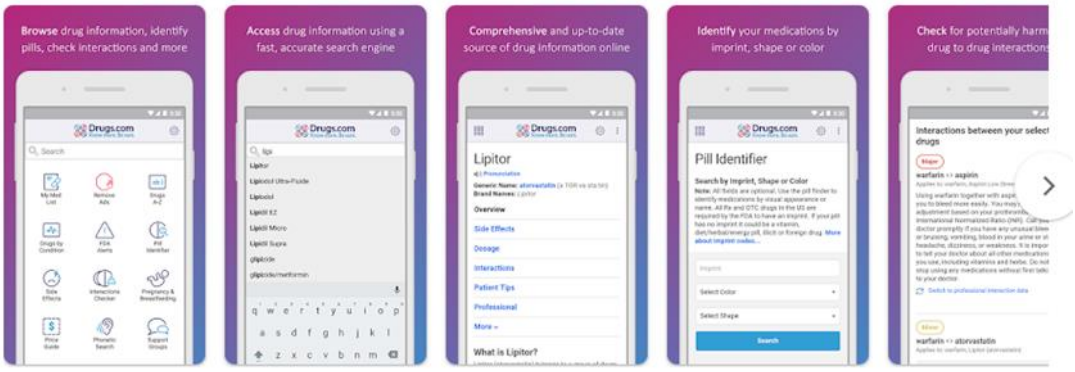
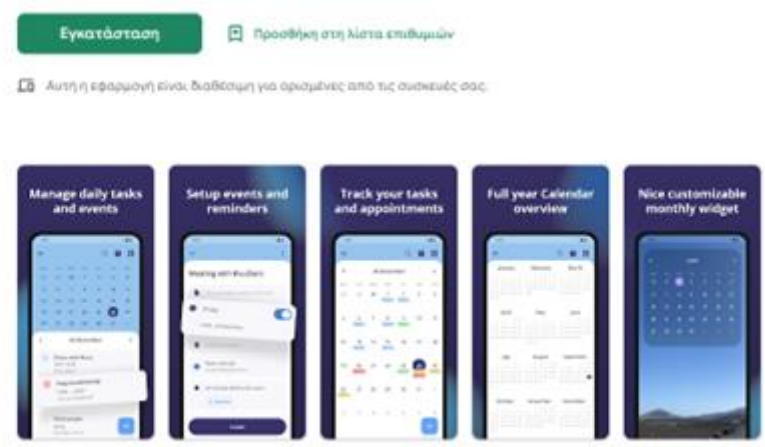
3. Drugs com Medication **Guide-free**



4. Calendar-free



5. Dementia/Digital Diary/Clock

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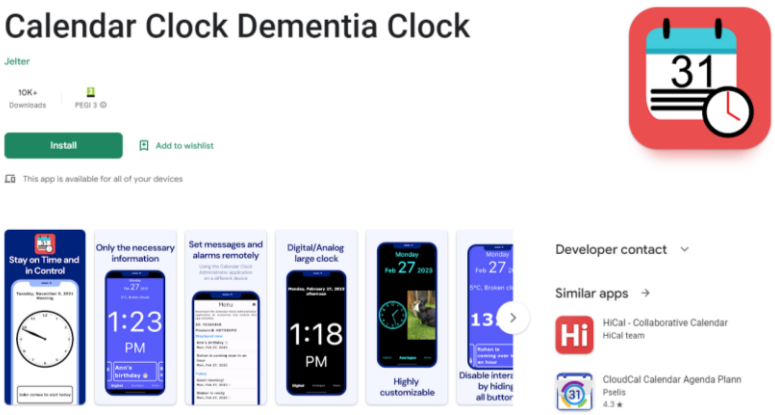
https://play.google.com/store/apps/details?id=com.fashmel.alzclock&hl=en

6. Calendar Clock Dementia Clock



https://play.google.com/store/apps/details?id=net.jelter.calendarclock&hl=en_US

CONCLUSION

Worldwide, more than 55 million people suffer from dementia and there are nearly 10 million new cases every year[1]. The annual global cost of dementia is now above US$ 1.3 trillion. The EU27 countries have currently more than 9 million people living with dementia (2018), with more than 16 million expected to suffer from the condition by 2050[2].

The use of mobile health applications in real surroundings have shown that they clearly facilitate the communication and planning capacities of people with mild dementia (Pwd) and help Pwds to engage socially and maintain an independent life for a longer time. No matter whether the type of technology is based on video or sound, it is clear that mobile health solutions are a beneficial addition to face-to-face communication between care professionals and persons with mild dementia and support them in their daily planning activities.[3]

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[3] Lindberg B, Nilsson C, Zotterman D, Söderberg S, Skär L (2013 Using infomation and communication technology in home care for communication between patients, family members, and healthcare professionals: A systematic review. Int J Telemed Appl 2013, 461829

[4] https://www.alzint.org/what-we-do/partnerships/world-health-organization/who-global-plan-on-dementia/

[5] https://www.who.int/news-room/fact-sheets/detail/dementia

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