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# ICT AND THE PEOPLE WITH DEMENTIA

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#### ABSTRACT

This review study focuses in the ways Assistive Technologies are used and the advantages they offer for the particular case of people suffering from dementia, a special brain condition form of disability which results to dramatic consequences in patients' and their caregivers' lives. The study describes how, through the use of such technologies, both patients and their carers are enabled to retain a certain level of quality of life and ease ordinary daily activities which would, otherwise, have been extremely difficult, if not impossible, to carry out.

Keywords: ICT, Dementia, Assistive Technologies, Disability

## 1. INTRODUCTION

An interesting paradox nowadays deals with an alarming demographic shift that mainly occurs in the developed countries. On one hand an increase in life expectancy, attributed to the advent of technological and scientific achievements, leading to a higher quality of life is experienced. On the other hand a clear rise of the syndromes and disorders associated with old age (which also needs to be redefined), such as dementia [1], diabetes, cardiac disorders, etc. comes as a counterweight in the modern way of life. Current estimates suggest an analogy of one elder for every four people of active working age. This "aging population" phenomenon, among other problems it causes, puts a serious burden on worldwide economic recovery from crisis and demands structural reforms in the National Insurance Systems. It, also, leads to the conclusion that a growing number of people are currently - and will be in the future - in need of some form of care or assistance to keep functionally independent in their daily needs and activities.

Dementia is a form of disability, a special condition of the brain, that has specific consequences in the patients' and their families' daily lives. In order to improve their quality of life and contribute in treating those individuals suffering an increasing number of advanced ICTbased systems and devices have been designed and developed that help mitigate the problems resulting from their physical and sensory deficiencies and/or support their caregivers.

### 2. AIM AND OBJECTIVES

The aim of this study is to describe the possible ways in which assistive ICT technologies can help people affected by the disease to improve their living standards, avoid social exclusion and achieve certain levels of independence, participation and communication with various social groups. More specifically the scope of this review is to answer the following questions:

-What is the definition of dementia, the description of its symptoms, its causes and clinical features?

-What is the definition of the term assistive technologies and what does it include?

-What are the benefits of the use of assistive technologies?

-What are the categories and examples of assistive technologies?

-What are the guidelines to deploy assistive technologies in these cases but also its limitations?

### 3. DEMENTIA

The Equality Act [2] defines a disabled person as an individual who has some disability "if he or she has a physical or mental impairment and the impairment has a substantial and long-term adverse

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effect on his or her ability to carry out normal dayto-day activities". Among the wide range of impairments referred to as disabilities the various forms of dementia are also included.

By using the term "dementia" [3] we refer to a group of degenerative disorders that often cause extensive changes in the brain structure that result in multiple signs of cognitive impairment and block the ability of, usually elder people, to complete activities of daily living. Usually the criteria to diagnose dementia include possible impairment in short-term or long-term memory and abstract thinking or judgment. In any case the impairments lead to significant social and occupational exclusion by progressively declining elder's cognitive functioning. Loss of memory (amnesia) is generally regarded as the most salient manifestation of dementia because of the fact that it characterizes Alzheimer disease, the most commonly identified of all dementia cases. However, it is not the only diagnostic characteristic since memory impairment is not a sufficient aspect of dementia on its own since a certain decline in one or more cognitive domains must also appear.

A more complete definition comes from Grabowski and Damasio [3] that describe dementia as "an acquired and persistent impairment of intellectual faculties affecting several cognitive domains that is sufficiently severe to impair competence in daily living, occupation or social interaction". This definition highlights two key issues, i.e. that of chronic progressiveness, along with the involvement of many different neural systems that leads to a decline from a previously attained cognitive level on a lower, incapacitating neurological condition. There is also, however, the static dementia caused by head injuries or other trauma.

What causes dementia remains yet to be explained. It is difficult to distinguish among the variety of causes identified as been associated with it. There is a set of prevalent symptoms in the majority of dementia forms, which are not mutually exclusive and may even coexist, causing confusion and uncertainty during the diagnostic process. The leading cause of cognitive impairment is considered to be the Alzheimer disease, pursuing a deadly course lasting between eight to twelve years. Alzheimer symptomatology starts from a gradual decline of memory and leads in memory loss. In the interims throughout its course there are various symptoms that affect patients' personality, including signs of visio-spatial disorientation and language confusion. In the final stage of the disorder/disease it evolves in extreme cognitive dysfunctions of high severity, like mobility difficulties, aphasia, or even lack of self-awareness or of the presence of other individuals.

Depending on the form of dementia a patient suffers from there can be numerous symptoms appearing. In case of vascular dementia, for example, slowing down of the thinking process, degrading problem solving ability, and facing difficulties in memory retrieval are noticed, while in front temporal dementia the most common characteristic is social misconduct. There are, also, cases of dementia, in the form of Parkinson's disease, in which patients have sleep problems, exhibit body imbalance which may frequently lead to falls, and in extreme cases may even suffer from delusions or hallucinations. As a rare form of dementia, the Creutzfeldt-Jakob disease is a form that allows no more than six months of life expectancy after onset, characterized by rapid decline of patient's cognitive capacities.

Finally, based on the perceived cause of cognitive impairment [3], like those described earlier, dementia can be classified into three main categories, those of primary dementia, dementia "plus" and secondary dementia. Alzheimer is an example of the primary dementia that presents abnormal signs in neurological level. The case of a neurological examination accompanied bv Parkinson disorders, like poor problem solving and decreased cognition, or cardiovascular disease falls to the second category of dementia "plus". Secondary dementia, e.g. brain tumor, is caused by medical or surgical conditions.

It is evident, from the above, there is a set of factors that contribute to the onset of a form of the disease, ranging from genetic, to biochemical and to psychopathologic or even environmental ones. Dementia has a dramatic impact on the daily life of both patients and their families causing restlessness, anxiety, depression, and even hallucinations, delusions or, in some cases, aggressive behavior. All these deteriorate social behavior, cause sleep problems and turn a patient generally to a person, incapable of performing daily tasks successfully. Complementary to treatment through medication, an available solution used for relief or even cure is the use of related assistive technologies.

## 4. ASSISTIVE TECHNOLOGIES

Assistive technology is a generic term commonly used to identify and include all those special kind of devices used from people with disabilities, to get assistance on and rehabilitation of their

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impairments. Assistive Technologies for people with dementia are designed and developed to help those people or their caregivers in routine activities and can either be simple stand-alone devices or sophisticated systems with related applications, requiring human intervention (e.g. communicate with a manned local call center). McCreadie and Tinker [4] suggest a first form of definition for Assistive Technology to be "any device that allows or assists an individual to perform a specific task otherwise not possible, or increases the ease and safety with which the task can be performed". "Computerized Cognitive Assistive Technologies" is another synonymous term used to refer to devices that potentially allow the elderly population to complete daily activities with a certain level of independence [5].

There are, also, many different terms widely used when taking about assistive technologies, e.g. "telecare", "telemedicine", "tele-health", and "smart/intelligent home" [6, 7]. These terms are frequently found in the literature, describing specialized tele-informatics technologies, as well as other communication technologies used to promote independent life of the elderly population suffering from dementia in their own homes. Moreover, Nakano et al. [8] explained that the use of such technologies in hospitals, health unit or other similar institutional settings, may provide great assistance to the medical staff and, at the same time, offer to relevant research valuable information about the specific needs of elderly population suffering from dementia.

To take it a step further, "Telecare", a form of long-distance provided medical care, is using ICT to enable elders suffering from dementia to remain in their homes with the safety and reassurance of a private place, instead of institutionalization [6]. The core aim behind those systems and related equipment is to utilize the advances and combination of computing and telecommunications, to facilitate dementia patients and offer a level of living with the highest possible degree of independence.

In the same study [6] we come across examples of "Smart / Intelligent Homes" using Information and Communication Technology installations to offer to their occupants control over a wide range of trivial activities or daily tasks and functions, providing at the same time communication with the external environment. The need for such Smart/Intelligent Homes was to automate various daily life problems and provide solutions integrated into a 'platform', an intelligent network environment which gathers and analyses data of inhabitants' movements, preferences and other meaningful information. Besides. comfort enhancement and higher levels of independence in everyday living, have been the self-evident facts of a series of tests having taken place in such experimental set-ups. These tests have shown that "smart homes" set-ups are beneficial for both elders and impaired people in general - and even more if there is a combination of both - allowing them to make use of systems with embedded artificial intelligence which reliefs them from either age problems or cognitive/physical impairments. In [7] an architectural example of a "smart home" scenario implementation, including mobile robots, sensor nodes and actuators is proposed. The subnetwork technologies employed include traditional telephone network, standard Internet access, wireless LAN, Bluetooth and RFID. In such architecture, the sensor and actuator nodes are responsible to send various messages - like emergency calls or simple data messages - while mobile robots are responsible for tasks related to validation and re-calibration of sensor nodes and data storage.

The main focus here is on such assistive technologies that aid patient monitoring – their activities and whereabouts – patient guiding when they exhibit disorientation, patient update on the need or time to perform specific tasks related to their health or treatment (i.e. time to take medication), and even carers awareness with warning alerts related to specific conditions. Assistive technologies are offering solutions in managing a variety of common risks that elders are susceptible to. They are able to limit and, in cases, prevent potential dangers ranging from falling accidents, fire hazards, slippery surfaces and floods due to negligence, to gas leakage and explosions.

### 5. ASSISTIVE TECHNOLOGIES: BENEFITS OF USE

In [3] one comes across two facts. The first deals with the median survival time, since the first symptoms appear, estimated to nearly six months. The second is the awareness of the difficulty from the patients' side to maintain a quality of life given that both their physical and cognitive conditions gradually degrade. Assistive technologies support their autonomy by reducing the problems for them and their caregivers.

The significant challenges, psychological effects of negative feelings and the pressure appearing in the lives of carers – be they companions, relatives, friends or care professionals – have been the

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objectives of a series of studies on the issue. A research study from Brodaty et al. [9] brings to the surface the low levels of satisfaction regarding the standard of living along with strong feelings of resentfulness. Additionally one of the earlier studies on the subject by Haley et al. [10] reveals the depression or anxiety these people experience. Bruce and Paterson [11] pointed that those feelings are originating from the constant need for patient supervision and just become worse due to the behavioral problems associated with the disease which need to be managed. Studies like this underline that the task of providing care to dementia patients is highly demanding - if not exhaustive - in multiple levels ranging from emotional and physical to even financial aspects.

Among the first benefits of use of assistive technologies, according to Hoenig et al. [12] a significant decrease in the hours of personal assistance. Another one, closely related to that, is the awareness provided to carers on how to share their experiences with other carers or professionals, or gather information regarding the nature and symptoms of the disease. Czaja and Rubert [13] provide such an example along with the design of a computer-integrated telephone system that allowed conference calls with other family members, caregivers and therapists. The purpose of this system was to enable access to available information on local or national caregiving resources and provide a link between carers and health professionals. Earlier attempts are noted by Gallienne et al. [14] presenting a ComputerLink network for the carers of Alzheimer patients, and by Mahoney et al. [15] who proposed the Telephonedlinked care for Alzheimer Disease, to deliver psychotherapy to family caregivers. Another attempt is the Swedish ACTION project [16] discussed by Magnusson et al. It is a good example of how caregivers can benefit from the use of ICTs.

When such formal community support services are unavailable, or even absent, the role of assistive technologies is vital. This is more frequent in remote geographical locations or rural areas with limited populations. In such cases, technology is critical in allowing patients to initiate and keep contact with their environment, communicate with community authorities and disengage, at least in part, their family and friends or neighbors from involved getting with their daily life responsibilities.

## 6. CATEGORIES AND EXAMPLES

There are basically 3 categories of assistive technologies:

• The nature of the intervention performed,

- The purpose served, and
- The point in time during the day they are used.

Boger et al. [17] explain the first category in which so-called "cognitive assistive technologies" monitor elder patients' activities, identify cases of patients in need for assistance and provide guiding instructions to prompt those to perform a particular activity or remind them of a special event. Additionally, they provide step-by-step guidance to enable the patients' self-service capability through routine activities and tasks like hand washing, toileting, and taking medication. Another example of this category, provided by Cohene et al. [18] is in the form of a project dealing with the memory training of Alzheimer patients through interactive multimedia and personalized life stories. The idea was to make use of reminiscence therapy, one of the most popular methods in dementia care practice, to help patients realize their identity. Through a variety of means consisting of digital images, videos, photographs and audio stimuli included in the system, memories are revoked to shape patients' experiences, sense of self and set of existing relationships, aiming at the reinforcement of a positive self-identity.

The examples of assistive technologies found in the second category address a variety of issues depending on the purposes they serve. Some prompt and remind patients to perform activities whereas others, like the electronic memory aids, use pre-recorded messages that can be played back [19]. There are, also, those dealing with "memory enhancement" [20] where some type of artificial intelligence robots provide reminders and - to an extent – engagement of social interaction. Memory enhancement is listed as being among the top objectives towards a treatment of the disorder thus several aid types have been developed to counterbalance memory decline or loss, and enable patients' abilities to remember familiar faces and perform daily tasks.

On the other hand, there are also technologies designed to simply monitor patients' daily life activities. Such "monitoring daily activities" systems tend to become pervasive [21] using intrusive equipment like microphones, cameras and wearable devices. Atallah et al. [22] suggested that for monitoring and assessing the elderly's daily routines, networks of wearable sensors, like pendants or bracelets, and ambient ones included and installed in the house appliances and furniture are being used. Also, Holmes et al. [23] give an example of a sensor system consisting of bed exit sensors, bedroom and bathroom monitors followed

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by an alarm for warning caregivers. The bibliography also includes non-intrusive sensor system cases, like those described by Campo and Chan [24] where the system provides information about potential changes in patient's physical and cognitive health. The researchers designed a surveillance system consisting of thermal infrared sensors, which is recording, observing and learning from the elders' movements and whereabouts. From the statistics produced from monitoring tasks, behavioral patterns are produced and help to medical staff is provided that allows them to detect any unusual events or take proper decisions regarding the medication given, the surveillance means, the patients' safety etc. The successful use of a system of infrared sensors to monitor and understand elders' rest-activity patterns is found in [8], while in [25] trackers were placed on patient's wheelchairs and an ultrasonic sensor system was developed.

Additionally, there are assistive technologies that focus on providing "guidance instructions" and "location information", in order to enhance patients' safety and protect them from various potential dangers like when their forgetfulness is during moments of excitement, or if disorientation happens during night wandering, or even from ordinary falls. Makimoto et al. [26] report cases with assistive technologies focusing in dementia patients' movement patterns to prevent potential falls, whereas Torrington and Tregenza [27] describe guidelines for appropriate home lighting to provide guidance and awareness of general location, existing obstacles and potential hazards in the house inner environment. Technologies like GPS, RFID and other forms of electronic monitoring, have been extremely useful tracking tools, widely used not only to analyze movement patterns, but also acting as locators for lost patients who are in need of assistance [28].

In short, there are projects developed to support a range of therapies which mitigate the disease symptoms and may include techniques involving light therapy, music therapy, or brain stimulation through cognitive tasks provision. Examples are given by Van Hoof et al. [29] who discuss the beneficial exposure to high-intensity bluish and vellowish light for institutionalized people with dementia, and by Chilukoti et al. [30] describing a system which incorporates a stationary training bicycle along with a GUI, aiming to promote both cognitive stimulation and physical exercise. A quick look at [8, 21, 23, 24, 25, 27] will provide to the reader additional information on devices available. Such devices and systems assist in "regulating", sort of, the sleeping patterns and face the disturbed sleep syndromes of patients with

dementia, such as "sundown syndrome" or "daynight reversal" as Bruer *et al.* [31] point out.

### 7. GUIDELINES FOR ASSISTIVE TECHNOLOGIES DEPLOYMENT

The need for guidelines to develop and deploy assistive technologies became apparent even from the early research attempts made on the field when the clear differences between the users' perceptions and the definitions of the problems, needs and functionality of those technologies were visible. This raised a need for a user-centered approach through which the designers have to identify users' needs, abilities – cognitive, psychological, etc. – and feelings towards the proposed technologies, so as to estimate the risk of developing impractical or unsuccessful systems. As identified by Cohene et al. [18], it is not the risks that should worry designers "but the failure to recognize such risks".

Moving in this direction Maciuszek et al. [32] attempted to develop a common frame of reference for users and designers aiming to facilitate the particular preferences and, hence, the co-production of such technologies in the future. Such an approach is based on the accepted assumption that the users of assistive technologies are experts on the subject because of their practical, experience-based knowledge, and continuously modified needs due to the progressive nature of dementia, so they should participate in the co-production of these technologies. Thus, in Robinson et al. [33] it is acknowledged that when users have been involved in scoping, participatory design and prototype stages of the systems development life cycle, effective and acceptable prototypes had been developed for devices. It is also shown that the users' expectations are for small size and weight devices that they are easily integrated into their daily lives, and so discreet, almost invisible, that will allow them not to be spotted or stigmatized as patients of dementia.

#### 8. LIMITATIONS AND BARRIERS

There are certain limitations and barriers related to both the development and the use of assistive technologies. When it comes to the user-centered design approach, as seen in [18], gradual decline of patients' memory, reasoning or judgment should be taken into account as among the most important barriers that may challenge the process. Such technologies are supposed to offer a high quality of life for a population of tremendously wide variety of behaviors that are modified continuously. Thus, it is self-evident that, without an average behavior pattern across a user population with so many individual differences, it is almost impossible to

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make generalizations about how best to develop assistive technologies.

Furthermore, several ethics and legal constraints are raised for the assistive technology developers, every time they attempt to develop a system using cameras, microphones, or wearable devices employing sensor technology. These are challenging issues that touch sensitive issues like invasion of a person's private life for the sake of cure or assistance on daily activities.

Another identified limitation comes from the side of the caregivers who, sometimes, become extremely reluctant to use the available services realizing that these could reduce their duties. This attitude may be explained either as an impulse out of guilt for receiving "external" help [13] or as lack of knowledge about the technology in use and, potentially, a stereotype based on negative expectations [9].

## 9. DISCUSSION - CONCLUSIONS

A patient with dementia may suffer from a wide spectrum of symptoms each a really difficult disability to overcome. How would one feel if her cognitive ability started to degrade and limit day by day? What if a person forgets who s/he is, what is her name, etc. because of problems in memory? What would it be like to depend on someone else to serve our daily needs? Can a person imagine the dangers a loved one is facing when hallucinating? These are only a small part of the symptoms and consequences the disease has, just "the tip of the iceberg'. Assistive technologies can be priceless, almost an enabler for daily survival with safety, relative ease and social inclusion otherwise unattainable.

It is shown in this review study that assistive technologies may be used as a complementary tool to improve the daily life standards in many ways. They minimize patients' social exclusion by offering them a decent level of independence and personal participation in their social circles and communication with them. They serve as a 'third eye' responsible either for the continuous monitoring of their activities and locations or, through the use of artificial intelligence technologies in "smart homes", their relief from the cognitive and/or physical disabilities and age problems associated with mobility limitations or cognitive degrade.

Furthermore, with the automation of daily processes dealing with their medication and treatment, they provide the needed levels of physical safety that would be threatened without a caregiver available day and night on their side. Such technologies will protect the patient from being lost in the streets of the city s/he does not recognize when being under the influence of a delusion or memory loss crisis, as an effect of the disease. Nor will they let the patients put their lives at risk by depending on if they will remember to take their medication in the proper dosage or time of the day they need to. In such cases, assistive technologies are a means of security and safety required to accompany the professional caregivers or informal carers coming from the family and friendly social groups.

It is also undeniable that assistive technologies cater for patients' psychological uplift, which is of critical importance in order to confront the disease. Patients are equipped with a positive attitude to give a fight with their problem when they realize that, through the use of such technologies, life is not over but just different than it used to be.

There are exceptional cases where assistive technologies shift their role, from the point of a complementary tool that helps improve their daily life, to that of the primary assistant for the suffering and those who support them. These are the cases of unavailable or totally absent formal community support services. It is implied that the vitality of assistive technologies in such a case is critical for patient safety and service of daily needs and activities.

Away from the 'micro level' of examining the uses of assistive technologies on a case-by-case basis, there is an important contribution of those technologies on a grand scale of the overall patient population. The massive data coming from the experiences of the use of assistive technologies may be used in two different dimensions. First, to spread awareness among the carers on how to share their experiences or get in touch with professionals for a more structured "education" on the disease. Second. even more important for research, to enhance the understanding of the patients' needs, habits and the most frequent symptom appearance. Thus, all the information gathered, helps lead the research efforts to evolve and improve the treatment of the disease and study its patterns with the hope that this might lead, eventually, to its cure.

The last finding of high importance is that assistive technologies have an indirect, positive, effect on the quality of life the dementia carers enjoy. This is realized by depriving from them all those negative feelings related to their loss of personal life, having to cater for a disabled person suffering from dementia. Assistive technologies allow the carers – formal or informal, professional or family – to have their "human" timeframes, relieved from the continuous, devastating feeling of

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someone else's safety being completely dependent on their presence.

There is always room for further investigation or suggestions for research that will result in the development and all the more better, more effective and useful assistive technologies. What came to the authors surprise from this study is that it is of equal importance to tackle the problems related to the caregivers of the persons suffering from dementia. The problems encountered by those responsible to take care of the patients are extreme psychological burdens, stress and feelings of inability to be away from the patient for their basic, daily human needs. It would be an interesting topic for further investigation to look into the way Assistive Technologies are in a position to bring in a balance for the caregivers, relieve them from the strains of continuous presence and allow them of quality personal and family time during the day, like any normal human being deserves.

The importance and value of Assistive Technologies is more than apparent given the numbers related to the disease as they are reported in the literature. These numbers are overwhelming and show that 28 million people are currently suffering from dementia worldwide. The trend is that this number will grow by 2040 to 81.1 million patients [1] which, by itself, suggests the world is facing a potential epidemic situation pretty soon. Moreover, an overall rate of dementia in the USA is between 6-8% among people older than 65 years, and the number of elder Americans affected by the disease will triple by 2050. It is a fact that chances to suffer from dementia increase with time and after a certain age (e.g. 60 years) this increase rate goes high proving the vulnerability of elders exposed to the disease. With such numbers, assistive technologies do not just "deserve" to be researched. Their further exploration, development and optimization becomes a mandatory task for research, being the leading countermeasure against one of the most serious and growing problems of our times. In a rather bold statement the authors believe that it is rather possible a very large number of elders in the future to suffer from some kind of disability or physical deficiency which will make assistive technologies even more critical for the well-being of the societies [34].

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