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DIGITAL TIMELINES- AN INTERDISCIPLINARY APPROACH TO DEMENTIA

Methodological
and case study
article

Keywords

Dementia
Digital
Memory

JEL Classification

I2

Abstract

The Digital timelines project (2014-1-UK01-KA204-000071) co-financed by the European Union under the Erasmus+ programme and coordinated by the Lancaster and Morecambe College, UK addresses the issue of dementia. The project relies on thorough research on dementia carried out in five European countries and aims at producing a training programme and creating digital resources which can encapsulate memory stimulating information from a variety of media to benefit specifically the person with dementia and their family and friends, as well as professional carers. New models of coordinated and non-pharmacologic rehabilitative care systems meeting the needs of individuals with dementia and their family members are imperative in order to respond to the increasing number of individuals living in the community with this devastating disease.

Introduction and context

Dementia is a universal phenomenon which is increasing at an exponential rate. It is estimated that there are currently 1.04 million (1.65%) sufferers in the UK, 270,300 (1.26%) in Romania, 32,000 (1.57%) in Slovenia, 331,000 (0.44%) in Turkey and 173,000 (1.82%) in Sweden. (Alzheimer Europe 2012 statistics) There are more than 10 million across Europe and 44 million globally. Directly linked to longevity, this is set to double over the next 20 years (<http://www.worldlifeexpectancy.com/cause-of-death/alzheimers-dementia/by-country/>).

Until, indeed if, dementia becomes curable, it represents an increasing cost challenge for governments, as well as an increasing social and moral challenge for humanity. These challenges therefore create demand by governments, communities and families for new, innovative and low-cost services which help to manage the progress of the disease, maintain the quality of life and help people stay away from expensive chronic support services.

This means that care for people with dementia is a growing industry and offers economic opportunities for European workers. Furthermore, the scope to use increasingly sophisticated ICT to help people with dementia is likewise a growth field, with new assistive technologies regularly coming on stream. Already, there are many types of therapies accessible to dementia carers, family, friends and professionals, which help the person with dementia to sustain the activity of the memory function and maintain good quality of life for as long as possible eg. compilations of favourite songs; written and photo-annotated 'life story' personal accounts.

The objectives of the Digital timelines project are as follows:

- to make maximum use of developments in ICT with regards to “multi-media” digital devices and associated progress in consumer access to produce a training programme and digital resources which can encapsulate memory stimulating information from a variety of media to benefit specifically the person with dementia and their family and friends, as well as professional carers. The effective resource produced is at very little or no cost.

The training package is easily transferable and accessible to individuals, carers, family and professionals alike. The training package can be cascaded on a one-to-one basis or in small groups. It can further be available as an eCourse, and can be supported by examples of digital timeline videos, as well as an instructional video, to ensure that the products are universally and freely

available as open educational resources, along with many other complementary support interventions.

The process of production and regular use of the final resource provides many hours of comforting support to the person with dementia and encourages greater memory based interaction between the person with dementia and their supporters.

The nature of the project also addresses EU priority needs, including: improving the digital skills of adults; improving the digital skills of varying age groups in the care industry, including younger adults entering the workforce; encouraging use of open educational resources (OER) and providing open and flexible learning; improving capabilities and knowledge exchange between actors in member states, including in practical application of ICT as an educational resource; a focus on the needs of the disadvantaged groups in society. Making the training resources available in Romanian, Slovenian, Turkish, Swedish and English addresses the need to produce Open educational resources in diverse European languages.

Previous initiatives

There are already a number of helpful and successful initiatives available throughout Europe which offer reminiscence-based therapy to people with dementia and their careers, personal reminders of people, places and events for the person with dementia. However, thus far there is very little available that uses a coordinated multiplicity of media to achieve a more powerful stimulation of memory and reminiscence (eg. photos, film clips, sound bites, personal messages both oral and video, etc.). Discussions with leading national dementia care bodies –such as Alzheimers UK and ZDUS, indicate that this represents a gap in therapeutic service provision, especially as ICT capacity and associated consumer accessibility develops. Furthermore, many of the interventions produced at an institutional level are neither tailored nor flexible to match the particular needs or interests in individual cases, which can often make them cumbersome to use and difficult to apply. The project offers both the possibility of multiple-media stimuli and a tailor-made production for each individual person with dementia and their careers.

Very few current initiatives are offered as a cascable course or eCourse with supporting materials. However, since the project does offer these, the capacity/ability to produce digital timeline videos is disseminated widely and at all levels of the dementia community - and indeed beyond to the “pre-dementia” elderly community - thus promoting accessibility. The basis of the Digital Timelines videos idea is partly from the success with the MyStory project in drawing in additional user groups because of the endearing

attraction of personal reminiscence to those who are able to directly identify and connect with it. This included large numbers of older people with dementia when disseminating the project. Conversations with some of these people and their carers indicated that personalized videos would stimulate more memories, if the correct triggers could be researched and included into the videos.

Different EU countries and cultures have different ways to cope with the needs of older people with dementia and other neuro-conditions and to deliver pastoral care. The variety of backgrounds and national policy contexts stimulates knowledge exchange, sharing ideas and best practice and finding common approaches to deal with this growth area. Each partner country is experiencing increasing numbers of older people, which means that not only dementia cases are on the increase but also the demand for skilled carers and people with a good understanding of dementia issues.

This project provides a valuable resource for upskilling those already involved in dementia care as well as for training those that enter this growing sector in the coming years. Each partner has a unique level of access to the direct and indirect target groups in each country and this offers scope to share and develop a range of approaches and applications of the project outputs.

In effect, the project uses new ICT capacities to pull together and build on successful therapeutic initiatives already available, which makes it complementary, but which also offers something more effective, more flexible and more widely applicable/accessible.

Project outcomes

- An international comparison report on current approaches, practices, examples of dementia memory support tools from the partner countries
- A training course for carers, families and friends of people with dementia; showing them how to go about the full process of producing a digital time-line video.
- A pilot training programme to test out the training course on partner staff (2) and cascade it to 10 active users in each partner country, resulting in 72 trained staff.
- Good practice examples of digital timelines videos (2 per partner - 12 in total)
- An instructional video on how to produce digital timelines videos (1 per partner - 6 in total)
- Three multiplier events held in Romania, Slovenia and the UK

Overview on Dementia situation in Romania

Dementia and Alzheimer's disease are legally defined as a disability in Romania. This is covered by Order no. 90 of 9 August 2002 which was issued by the Ministry of Health, State Secretariat for Disabled People and published in the Official Gazette no. 701 of 25 September 2002. However, according to the Romanian Alzheimer's Society, the methodological norms have not yet been established, which means that so far this definition is mainly theoretical and does not translate into practice 2. Alzheimer Europe estimates the number of people with dementia in Romania as being 270,304. This represents 1.26% of the total population of 21,387,517. The number of people with dementia as a percentage of the population is somewhat lower than the EU average of 1.55%. One in six patients in hospitals and half of the residents in old people's homes suffer from dementia. Unfortunately less than 20% of seniors have been consulted and diagnosed and most of them get a diagnosis in the advanced stage of the disease. Their chances of rehabilitation and access to information and proper care and treatment are dramatically limited. By 2025, it is estimated that the number of persons with dementia will increase to around 600.000 in Romania (<http://www.alzheimer-europe.org/Policy-in-Practice2/Country-comparisons/Legal-capacity-and-proxy-decision-making/Romania>).

Priorities and strategies

Mental health is among the national healthcare priorities in Romania. In terms of treatment pharmacological treatment prevails; patients in the advanced stage are hospitalized. The psychiatric hospitals are very "medically" oriented. Patients' rehabilitation is difficult because doctors' work is based on the biological model of mental illness. The staff has a 'paternalistic' approach to the patients, that is people under their care are protected and provided for but they are not given any responsibility or freedom of choice (even in relation to patients' treatment process). The patient has played a passive role in his or her own treatment process. Since 2006, hospital directors have managed their budgets independently but they have enjoyed limited freedom in hiring their staff. There is a shortage of staff in most hospitals. There have been some attempts to improve the situation: Ministry of Health has increased psychiatrists' salaries and opened more positions for this field.

A new stage in dealing with this health issue was February 2012, when the National Alzheimer Alliance was set up and this was the first step in lobbying for a National Dementia Strategy (<http://www.alz.ro/>). There are huge difficulties in obtaining an early diagnosis. GPs are not permitted to diagnose dementia. Only psychiatrists, neurologists and geriatricians are permitted to diagnose dementia and/or Alzheimer's disease.

Continuing education is an obligation for GPs although courses on the diagnosis and management of patients with dementia are not compulsory. There are guidelines approved by the National Health Insurance, which prescribe a series of examinations that need to be carried out when making a diagnosis (neuropsychological tests, CT or MRI scans and laboratory tests). The current "Guidelines for Dementia Diagnosis and Treatment" were published in 2009 with the approval of the Health Ministry. These guidelines were developed by neurologists and psychiatrists and undertaken by all the specialist doctors involved in the diagnosis and treatment of dementia (neurologists, psychiatrists, geriatricians). Medical treatment at national level is free of charge; AD drugs are available and reimbursable in Romania. Treatment initiation and treatment continuation are restricted to specialists (neurologists or psychiatrists).

Legislation relating to the provision of home care services

There are several laws which relate to home care services (but only medical services). There are also laws regarding people with disabilities which also cover people with dementia. There are two laws regulating the activity of personal assistants i.e: law 519/12.07.2002 and Romanian Government Decision no. 427/2001 regarding the approval of Methodological Norms for working, rights and responsibilities of personal assistants for people with disabilities (<http://www.alzheimer-europe.org/Policy-in-Practice2/Country-comparisons/Home-care/Romania>).

GPs or specialists recommend medical home care by taking into account the state of health of the person in need (who must have a health assurance) and the person's dependency grade. Medical home care services are based on contracts signed between the National Health Insurance Company and people or organizations accredited to provide such services. There are 3 dependency grades: totally dependent, partially dependent and independent.

A person can apply for medical home care (not for a personal assistant, but for medical personnel – nurses) on condition they have been previously hospitalized for their disease, he/she has been recommended medical home care by the specialist/GP who has a contract with the National Health Insurance Company; the medical care providers

have a contract with the National Health Insurance Company.

A person with a grade one disability certificate is provided with a personal assistant if he/she has a diagnosis of dementia from a specialist (psychiatrist, neurologist) and a form describing the evolution and symptoms, which demonstrate the need of permanent supervision. An Expertise Commission for Persons with Disability will

examine the patient and his/her medical documents and will decide on the grade of disability. The patient or the family have to find a person willing to become the personal assistant. The personal assistant is paid 8 hours' work per day by the local authorities. Their activity is monitored by representatives of the Social Protection Departments. Personal assistants must complete training programmes offered by local authorities. The patient's condition is periodically revised by the Commission (<http://www.alzheimer-europe.org/site/Policy-in-Practice2/Country-comparisons>).

There are two types of certified carers (as they appear in the Romanian Occupational Code): home carers for people who are ill and home carers for elderly people. They are certified on the basis of Government Ordinance. 129/200 and they are legally certified by the Ministry of Employment. Their training should be organized by providers who have been accredited by the National Council for the Professional Training of Adults. A certified carer needs a six-month training program, which is longest training in the field. Most people cannot afford to pay for the course and as a result there is a shortage of qualified staff. (<http://www.alzheimer-europe.org/Policy-in-Practice2/Country-comparisons/Home-care/Romania>).

National guidelines on therapeutic interventions

There are some general interventions which are available in Romania to support the persons with dementia and their carers, in all forms: e.g. books, memory box, any visual triggers (cartoons), gadgets, positive images, self-help groups, other activities within European projects provided by health/social care, NGOs, local initiatives, day/night centres.

The most accessible interventions are those organized by families and self-help groups. Such activities are very popular:

- Creating a choir/ participating in a choir
- Creating a group of friends who meet regularly
- Listening to music
- Reading books
- Doing crossword puzzle
- Playing cards/ monopoly
- Visiting museums
- Playing with grandchildren
- Taking care of animals/ plants
- Working in the garden
- Going to a fitness club with friends
- Cooking with friends

There have been several project proposals from local authorities (municipalities) to open day care centres in some of the major cities in Romania. There are several day care centres in the country which benefit from the support of the Church but

they are for elderly people with social problems and not specifically for people with dementia.

European projects: Bearing in mind that one of the main challenges Europe is facing nowadays is the ageing of its population, there are lots of European projects whose target groups have been seniors. The following projects show how stimulating they are in engaging seniors in activities and how much they can help seniors to stay active as long as possible.

The Bilfam project proposes a program ('the 'Narrative Format' innovative methodology) for learning a foreign language within the family (children/ parents or grandparents). Field research results have shown that parents/ grandparents with little or no foreign language competence, provided with the necessary tools and strategies, can be involved in their child's foreign language learning. Both child and adult benefited from the experience intellectually and emotionally. Results also showed that parents/grandparents felt encouraged to improve their own language learning and computer skills as they taught their children/grandchildren. MyStory is a project funded by the European Commission (under KA3 ICT) for the years 2011-2013. The two primary beneficiary categories were senior citizens and young people, who were expected to interact while sharing learning and providing support for each other. At the core of the project lay a collection of life-stories, narrated and shared by senior citizens and collected by younger people (who were recruited and trained as digitally competent story collectors and gatherers). The collection was made available online and accompanied by a complete set of user information packs and background contextual materials. In their turn seniors were taught how to use the computer and the internet. The Grankit project funded by the European Commission (under KA3 ICT/GRUNDTVIG Multilateral) and implemented by Euroed Foundation, Iasi, Romania, has also helped address the same challenge. The project has raised the issue of 'being an active citizen' regardless of the age or the role in society by exploring the relationships between generations (grandparents and grandchildren), encouraging solidarity between these groups and promoting strategies for ensuring that the ageing can be positive and dynamic. Grandparents have been trained to acquire basic ICT skills and use social network groups (such as Facebook) by their grandchildren. In their turn grandparents are supported to set up a "Grands Help Desk" on the internet, which provides online support to children and teenagers (help with homework, personal or family problems, bullying etc.).

Alzheimer Cafes: The Romanian Alzheimer's Society and a group of business people set up an Alzheimer Cafe (AC) in Romania, in Bucharest, in 2012. "An Alzheimer Cafe is a new type of support

that takes the form of a monthly gathering for the purpose of education about dementia, support and social contacts. The cafe is for people with all types of dementia and is the first type of support that brings together people with dementia, their family carers, professionals and volunteers. The AC model was developed in the Netherlands in the late 90s". The opening of the cafe was attended by international experts in the field, who also held a Master Class for dementia specialists about developing dementia-care in Romania. The Alzheimer Cafe has become more than a social gathering by offering support to the people affected from volunteers, carers, and professionals who are present at the Cafe. It provides dementia care and psychological education about how to live with it. The Alzheimer Cafe is a relatively inexpensive form of care intervention, and free to everyone who attends. Costs are covered by donations, therefore the Alzheimer Cafe relies heavily on voluntary input from Professionals and volunteers. (<http://www.romania-insider.com/comment-alzheimer-cafe-concept-close-to-reality-in-romania/58099/>)

The use of the internet/computer in families: In Romania children spend a lot of time with their grandparents while parents are at work. Grandparents supervise their grandchildren and if they can, they help them with homework. Sharing experiences and knowledge is mutual. It stands to reason that if there is a computer in the house, seniors have been taught how to operate it and play computer games, use youtube or watch films by their grandchildren. Playing computer games and watching films online has become a way of spending time for some seniors (popular site: <http://www.proprofs.com/games>; <http://www.brainmetrix.com>; <http://www.gamesforthebrain.com>; <http://www.lumosity.com/app/v5/personalization/memory>; <http://www.mastersofhealthcare.com/blog/2009/100-awesome-anti-aging-brain-games-online-and-off/>). The most fortunate seniors have learnt how to use Facebook and Skype in order to stay in touch with their nearest and dearest.

Conclusions

Although mental health is among the national healthcare priorities in Romania we still need a solid strategy in the field to provide directions, standards and coherent plans of action. Given the growing number of patients, although below the European one, it is imperative to raise public awareness about the issue and stop considering it a burden to be hidden. Therefore, a common National Dementia Strategy is more than welcome. The illness and its treatment involve several fields; our system still lacks an interdisciplinary approach of psychiatric and neurological pathology. Funds should be allotted for research in the field.

Policy advocacy for advancement of new interdisciplinary rehabilitative care systems are imperative in order to meet the needs of an increasing number of individuals living in the community with this devastating disease. Research has highlighted the following issues:

- the need for training and support for caregivers
- the need to achieve a better life quality of the people with dementia and those around them (raise awareness about the condition and also focus on teaching caregivers to deliver treatments to the persons with dementia)
- the need to improve hospital conditions
- the need to use multiple techniques, including behavioural skill training, communication, social engagement, and sensory and environmental stimulation in a variety of settings, including long-term care and private homes. More and more voices claim that the pharmacological treatment is not the only one and other means should also be used. Although the evidence we have is little there is no doubt that these therapeutic methods bring about favourable effects in reducing behavioural, social, emotional, and cognitive problems of the people with dementia
- the need to work towards the rehabilitation of the patients.

- the need to educate population to have a medical check is essential- an early diagnostic could alleviate much of the patients' and families' suffering. A late diagnosis limits patients' chances of rehabilitation and access to information and proper care and treatment.

Furthermore we expect that the findings of the project and the tools and resources developed as a result of our work will have positive benefits for care workers and their clients by facilitating CPD for workers, encouraging pathways for progression, encouraging policies that will facilitate new methods in the care environment and in raising the profile of care issues, dementia and the aging population more generally.

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