

Dementia

Overview

Worldwide, around 50 million people have dementia, and there are nearly 10 million new cases every year. It mainly affects older people, but is not a normal part of the process of ageing. Dementia is one of the major causes of disability and dependency among older people worldwide and has a physical, psychological, social, and economical impact, not only on people with dementia, but also on their carers, families and society at large. The organisation of care and provision of support to people with dementia is of complex nature as includes many elements such as early diagnosis in order to promote early and optimal management, optimising physical health, cognition, activity and well-being, identifying and treating accompanying physical illness, detecting and treating challenging behavioural and psychological symptoms and providing information and long-term support to carers.

Care Delivery Shortcomings

Cognitive stimulation and risk reduction

Lack of knowledge of dementia causes:

There is not enough evidence about the protective and risk factors causing dementia, neither efficient strategies for prevention as for other illness such as diabetes or heart attack.

Lack of awareness and stigma on mental health:

Around the world is still being a lack of awareness and stigma around mental illness. Consequently, there is not special for mental health, lacking promotion of psychological wellbeing and cognitive stimulation targeting risk population, such as the elderly group.

Socio-economic disparities exist:

Elderly is a heterogeneous group, existing socio-economic disparities among them. This could be a greater barrier to access to leisure activities or physical programs, as well as ICT-solutions for cognitive training.

Care or family responsibilities:

During this stage of life there are new responsibilities to attend. For example, most of the couples have to take care of their grandchildren, furthermore, when the need for care of one of the parts of the couple, the other supports and takes care. These situations may facilitate the elderly quite their own time for leisure and sometimes overwhelming themselves.

New technologies are sophisticated:

Current smart phones, smart watches and sensors have sophisticated features, and target groups are not comfortable using ICT-solutions.

Lack of bi-directional connectivity of devices:

Connectivity is another issue with most products on the market. If connectivity is available it is unidirectional, only supporting transferring values out of the device. Any input, including adaption to therapy parameters, therefore needs to be manually set. There are innovative, medical grade devices, but these tend to be costly and therefore only suited to research use rather than widespread adoption.

No real harnessing of ICT and technology features in health promotion:

ICT-based solutions are not widely used by health care systems, and these solutions are just piloted but not adapted to real contexts. Online tools found are limited, and not integrated even with health records.

Lack of coordination integrating mental health care with different sectors:

Leisure, tourism and physical activities are not integrated on the public mental health agenda for the elderly population.

Early detection and diagnosis

Lack of knowledge of dementia causes:

There is no evidence about the cause of dementia, neither efficient strategies for prevention.

Lack of awareness and stigma on mental health:

Around the world is still being a lack of awareness and stigma around mental illness. Consequently, this situation hinders early detection and diagnosis.

The operation of the current risk assessment is imperfect:

Current tools for assessment's sensitivity for the early detection is very low. In this regard, nowadays a diagnosis requires investing a lot of time with the patient, physical explorations, and brain scans. Consequently, health care providers require a huge investment of time and training to diagnosis dementia.

Patients are often not reached early enough:

Studies show that in the world there are eight million people are not diagnosed. Moreover, the estimations around the ageing of the population help to calculate that these numbers increase to 152 million people by 2050.

Personalised support and chronic care for dementia

Socio-economic disparities exist:

Elderly are a heterogeneous group, existing socio-economic disparities among them. This could be a greater barrier to access to services, as well as ICT-solutions for supporting cognitive rehabilitation or independent life at home.

Lack of evidence:

There is a lack of studies on the success of non-medical treatments mediating the loss of cognitive functionalities. Both neurocognitive and psychosocial rehabilitation programmes have shown encouraging results but there is not a conclusion on the main benefits for people with dementia.

Lack of personalised treatments:

People with dementia participate in different programmes for neurocognitive and psychosocial rehabilitation such as cognitive stimulation therapy, group-based interventions or reminiscence therapy. Nevertheless, there is as yet very little known about which therapy is more effective for each case.

New technologies are sophisticated:

Current smart phones, smart watches and sensors have sophisticated features, and target groups are not comfortable using ICT-solutions.

No real harnessing of ICT and technology features in cognitive rehabilitation:

ICT-based solutions are not widely used by health care systems to promote cognitive rehabilitation, and these solutions are just piloted but not adapted to real contexts. Online tools found are limited and not integrated even with health records.

No real harnessing of ICT and technology features in promoting independent life:

ICT-based solutions are not widely used by social and health care systems to promote independent life of people with dementia, and these solutions are just piloted but not adapted to real contexts. Tools found being applied in real contexts are based on improving communication between caregivers and the person with dementia, but not integrated even with health records. There is a need for integrated ICT-tools addressing different domains such as improving communication with caregivers and supporting independence life for people with dementia. Inputs from the use of these tools may be integrated on social and health care systems, for example, the study for the reasons if the person falls and eliminate the possible risks at home.

Caregiver support

Socio-economic disparities exist:

Caregivers are a heterogeneous group, existing socio-economic disparities among them. This could be a greater barrier to access to services, as well as ICT-solutions for supporting caring and reduction of the burden of care.

Integrated tool for caring is missing:

ICT-based solutions are not widely used by social and health care systems to support unpaid care/Caregivers at home, and these solutions are just piloted but not adapted to real contexts. Tools found being applied in real contexts are based on improving communication between caregivers and the person with dementia, but not integrated even with health records. There is a need for integrated ICT-tools addressing different domains such as improving communication and supporting independence life for people with dementia. Inputs from the use of these tools may be integrated on social and health care systems, for example, if there is or not a following-up of the medication's reminders.

Tools for the burden of care reduction are missing:

There is a lack of ICT-solutions focused on the mental health of caregivers, giving them therapeutic counseling and resources to reduce their feeling of burden/overwhelm by caring a person with dementia.

Monitoring and review

Missing simple tools with integrated scores for monitoring dementia.

Simple tools are not comprehensive enough measuring just one domain regarding dementias' progression because they are lengthy and/or cover only a particular domain.

Lack of practical tools for real contexts.

There are many tools available today to gauge the presence and severity of dementia symptoms through caregiver observation and report. However, most are best suited for research studies.

Lack of bi-directional connectivity of devices:

Connectivity is another issue with most products on the market. If connectivity is available it is unidirectional, only supporting transferring values out of the device. There are innovative, medical grade devices, but these tend to be costly and therefore only suited to research use rather than widespread adoption.

No real harnessing of ICT and technology features in monitoring:

ICT-based solutions are not widely used by social and health care systems, and these solutions are just piloted but not adapted to real contexts. Online tools found are limited, and not integrated even with health records.

Training and Education

Lack of personalised dementia education and training:

Dementia education programmes are not personalised to caregiver's level of knowledge and not personalised to the different dementia's stages. Current health system efforts to proactively empower patients with (or at risk of developing) dementia through training are usually not tailored to individual needs. There are some public awareness campaigns and peer group meetings, but these do not and cannot accommodate all patient and caregivers needs.

Overall low use of ICT:

The state of the art in training and education is characterised by a very low degree of ICT use. Multi-media use is very rare. Online portals provide mostly text information and lack the link to a local contact person. The content is not tailored to the patient's stage of cognitive functionality, medication prescribed and concomitant diseases, which confuses patients with information not relevant for their condition (too much or not adequate).

Lack of motivational features and skills gap analysis:

The existing education programmes do not contain any motivational features, and not all test for knowledge gain.

Lack of informal carer training and support:

Often, family carers seem to have to adapt to the changes that dementia affected their relatives and seek alternative ways of securing the resources they need for managing their lives. They express that they had not been prepared adequately for the caring role or assessed satisfactorily in terms of whether they could manage given their skill level, age and/or health status

Lack of lifelong learning activities :

The existent learning activities are based on short-term activities, even when dementia is a life condition, generating new challenges with time, when the patient needs greater care.

Professional collaboration and coordination

Fragmentation prevails:

In most public health systems around the world, fragmentation and poor coordination of care have been the greatest obstacles in ensuring adequate cognitive rehabilitation and care of people with dementia.

Health and social care professionals are also affected by the lack of information:

The records that each of them holds about the patients are not shared across care environments, resulting in the fact that they must obtain medical information from the patient and re-administer tests when new patients arrive in their system of care.

Lack of analysis of needs of patients:

People with dementia are treated by their illness, but these are not shaped by their own needs.

Shared, personalized decision support

Exclusion from the process of decision making people with dementia :

Existent services are not yet being widely accessed by people living with dementia.

Overall low use of ICT:

The state of the art in shared, personalised decision support is characterised by a very low degree of ICT use. Multi-media use is very rare. Online tools to facilitate interaction among relevant stakeholders are not widely extended.

Fragmentation prevails:

In most welfare systems around the world, fragmentation and poor coordination of care have been the greatest obstacles in ensuring adequate cognitive rehabilitation and care of people with dementia. In this regard, health and social care is provided by professionals without coordination.

Integrated Care Procurement Objectives

1. Address integration with other sectors such as tourism, leisure and physical activities for elderly people with health. Targeting cognitive stimulation through tourism, leisure and physical activities has shown positive results on literature, but the offer of different evidence-based ICT-solutions for risk population is not wide.

Related Integrated Care keywords :

- DIGITAL HEALTH
- HOLISTIC AND COMPREHENSIVE APPROACH
- PERSON-CENTRED

2. Address the lack of time of professionals for consults by longitudinal screening programs targeting elderly population in the community promoting awareness: Longitudinal screening programs will inform healthcare providers about the cognitive and functional competencies of the population at risk. Moreover, a community-based screening programme will promote awareness combating and eliminating stigmas on mental health.

Related Integrated Care keywords :

- DATA AND INFORMATION SHARING
- WORKFORCE RESOURCES, TRAINING AND CAPACITY BUILDING

3. Address the lack of ICT-solutions promoting cognitive rehabilitation. This should include the integration on tools and solutions with health records.

Related Integrated Care keywords :

- DATA AND INFORMATION SHARING
- DIGITAL HEALTH

4. Include relevant stakeholders such as social carers and pharmacies in prevention: The interface to patients and their access to services should capitalise on the fact that social workers and pharmacies can be in frequent contact with at-risk patients and so can play a strong role in prevention and early detection.

Related Integrated Care keywords :

- CARE TEAM BUILDING
- HOLISTIC AND COMPREHENSIVE APPROACH

5. Adjust the feedback of the data from monitoring to new care strategies. Data derived or collected through clinical observation and the use of available technology, has to be translated on personalised social and health care strategies avoiding the lack of bi-directional connectivity of devices.

Related Integrated Care keywords :

- DATA AND INFORMATION SHARING
- DIGITAL HEALTH