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CARE Campus. A European Consortium Model to Support Formal and Informal Caregiving Training

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Abstract

Today's health and social care systems are facing a challenge in how to effectively address caregiving for ageing populations facing cognitive disorders and frailty. Scholars and policy makers are now identifying a rise of "hidden form of care", e.g. informal caregiving, as a phenomenon in support for ageing populations. Across Europe for instance, the rise in the older old adult population has led to a rapid expansion of the number of carers, both professional (formal) and informal. The latter, representing mostly family members caring for their loved ones, truly represents a "hidden form of care". This can be a problem if formal and informal caregivers are not fully integrated into the healthcare continuum or are not given a systematic support to carry out caregiving in a relevant and safe way. There is currently no comprehensive European-wide legal framework and support mechanisms, in terms of training and education for this group. CARE Campus, an EIT Health programme within the Educational Campus Pillar, is a new model of collaboration between academic institutions, the private sector, and the public sector whose main aim is to support the development of a comprehensive training for formal and informal caregivers in Europe. The initial phase of the development encompasses nine (09) online training modules with a quality control process to ensure that the curriculum is evidence-based, compliant with the national and local regulations, and addresses the needs of caregivers across Europe. The objective is to support formal, informal, and family caregivers and reduce the burden on health care systems, whilst improving the quality of care for older adults.

Introduction

Challenges of Healthcare due to an Ageing Population

Ageing is undeniably one of the major socio-economic and healthcare challenges that societies need to tackle. Its impact on the global economy, public policy, society and healthcare are only just beginning to be fully grasped (1). In Europe, individuals aged 65 and over are expected to reach 30% of the population in the year 2050 (2). Compounded with considerable lifestyle, environmental and genetic factors, ageing is commonly associated with frailty and an increase in the prevalence of non-communicable diseases (NCDs) including dementia, coronary heart disease (CHD), stroke, chronic obstructive pulmonary disease (COPD), cancer, and type

2 diabetes mellitus (DM); all of which are the leading causes of adult death and disability worldwide (3, 4). With the abysmal success rate of the pharmaceutical research and development (R&D), and in the absence of effective therapies, in spite of significant industry efforts in the last two decades (5), persons with dementia require continuous management and care that is costly and inefficient. Regrettably, current models of healthcare services are still mainly focused on episodic and acute illnesses, rather than chronic conditions and long-term care needs. In a recent study, it has been estimated that, in 2015, 46.8 millions people worldwide live with dementia and have an estimated annual healthcare cost of 817 Billion US dollars (6); this expenditure is expected to surpass the trillion US Dollars

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threshold, by the end of 2018.

Frailty in relation to ageing is associated with an increased risk for adverse health outcomes and restrictions in completing necessary activities of daily living (4, 7). Frailty is conceptually difficult to define based on current literature, yet the frailty is a criterion for older persons to receive social welfare in some country contexts. From the perspective of health and social care services, frailty in later life is seen as a state requiring an integrated healthcare pathway from early identification of frailty through screening and appropriate preventative health interventions to improve personal health and well-being, to better management and treatment of associated acute and chronic health events (8). Finding integrated methods in working with frailty in later life is also relevant from a health economic perspective. As longevity in the population increases, there is a risk for an increase in the demand and the cost of healthcare and social care (9). This necessitates a systemic reform of healthcare delivery systems to become integrated and patient-centered (10). Moreover, it is also important to note that the commonly used concept of frailty in medical literature generally uses a normative framework as reference point, which results in that frailty is situated at the polar opposite end of healthy or active ageing spectra. This means that the concept of frailty can lead to a conceptually unhelpful separation of successful agers from the unsuccessful (11). Thus, it could be argued that frailty is useful from the perspective of communicating the state of needing a palette of support services, but that it is equally important to actively work with the concept in order to avoid the pitfall of placing frailty on a unhealth-health spectrum or stripping the concept of personal agency in later life.

Formal and Informal Caregiving

For over two decades, aging in place has informed aging research and policy. Supporting older adults to the greatest possible degree in their home communities and home environments has been a priority. However, as international migration has become more prevalent, the idea of supporting older persons in their home environment has been challenged (12) and it has also led to tensions in the meaning and implications of caregiving in everyday life. Across Europe, the limitations of the healthcare and social care systems to effectively address challenges related to ageing, have led to a rise of

“hidden forms of care”, e.g. informal caregiving, as one of the mechanisms that support ageing populations (13). While caregiving sits unduly at the fringe of the healthcare economy, it is increasingly recognized not just as the backbone of long-term care and its most reliable resource, but also as an important aspect of the economic challenges facing healthcare sustainability and quality (14). In a recent study, informal caregiving for patients with dementia was estimated to represent 41.5 billion US dollars in the United States, most of which is not commonly included in estimating the total toll of ageing on the healthcare system (15). In Europe, while variations among countries exist, it is estimated that 34.4% of the population are informal caregivers with the highest percentage in Finland (43.6%) and the lowest in Hungary (8.2%) (16).

Whilst informal caregivers are unpaid family members or friends caring for their loved ones, formal caregivers are salaried professionals. They provide care and other caregiving services in special care facilities or at home. Formal and informal caregivers together make up a substantial group responsible for a wide range of care activities for older adults such as personal care (e.g. feeding, dressing, bathing), companion care (e.g. conversations, companionship, booking appointments), household services (e.g. cooking, cleaning, arranging transportation), and health-related activities (e.g. medication). Although caregiving is of vital importance for many, it is not yet fully integrated into the healthcare continuum. There is no Europe-wide legal framework governing the legal responsibilities for formal and informal caregivers (17). Even the relationship between formal and informal caregiving is not well defined. Some European countries, e.g. the south and eastern parts of Europe, regard informal caregiving and formal caregiving as substitute to health provisions; whereas in Northern Europe, they are regarded as complementary to each other (18). Although being a carer can be challenging and may need structured support, this support is either nonexistent or inaccessible. Therefore, training and counselling has been recognized as a critical component to support caregivers and a critical resource of a sustainable healthcare system (19). The current supply gap must be addressed with an increase in the elder caregiver workforce and it is crucial that these individuals and family caregivers are adequately educated to handle the specific challenges associated with caring for

older people. The Caring and Ageing Reimagined in Europe (CARE) consortium, founded as part of the Educational (Campus) Pillar of EIT Health in 2016, conducted and published an in-depth landscape report, led by the Global Coalition on Ageing (20).

In this paper, we report an example of an innovative project, CARE Campus is a new model of collaboration between academic institutions, the private sector, municipalities and non-governmental organizations (NGOs) to support the development of a comprehensive training for formal and informal caregivers in Europe. This collaboration is supported by the European Institute of Innovation and Technology for Health (EIT Health).

CARE Campus EIT Health

The European Institute of Innovation and Technology for Health (EIT Health) is a novel collaboration model established by the European Union in 2015. This initiative is part of a wider European Union initiative: the European Institute of Innovation and Technology (EIT) which was established in 2005-2006 “[to] redefine the mandates and governance of Higher Education institutions as part of a Knowledge Based Economy route to economic and social development” (21). Built with the philosophy of developing a new integrated “Knowledge Institution”, EIT Health combines higher education, research, and innovation to tackle the most complex and daunting issues facing the healthcare systems in Europe and to improve healthy living and active ageing of its citizens. EIT Health is composed of more than 140 leading European health-related organizations, including academic and research institutions, hospitals, pharmaceutical companies, medtech laboratories, and public sector members. EIT Health supports annually several projects and initiatives in Medtech innovation, entrepreneurship and accelerator programs, and educational initiatives. Each year, the selected projects are co-funded by EIT Health and the partnering institutions for at least one year. In 2016, EIT Health approved Caregiving and Ageing Reimagined for Europe (CARE Campus) as a funded project.

Caregiving and Ageing Reimagined for Europe (CARE Campus)

CARE Campus aims to establish an online educational training course for caregivers,

both formal or informal, in Europe. Its primary objective is to launch an e-based School for Carers. Led by Imperial College London since its inception, the lead Institution will transition to Karolinska Institutet in 2019.

Aim: The mission of CARE is to increase the numbers of new professional caregivers and improve the quality of care delivered to older adults. It aims to educate and train caregivers for all settings, including home care and traditional institutional care. The CARE e-based School for Carers for the ageing adult strives to meet seniors’ needs, address age related caregiving demands for families and communities, to reduce hospital and physician costs, and to be a driver of economic growth.

Description of the Curriculum Content and Design Process

At the core of CARE Campus is the development of a comprehensive online training modules for formal and informal caregivers. The curriculum has been designed with the collaboration of academics, health professionals, policy experts, and caregivers. The initial phase of the development encompasses nine (09) modules. Furthermore, a quality control process has been established to ensure that the curriculum is evidence-based, compliant with the national and local regulations, and addresses the needs of caregivers across Europe. The curriculum content is outlined below.

Curriculum Outline

A. Introduction to Caregiving for Older Adults

This course is an introduction to providing care and support for older adults, senior citizens, or the elderly. The course has been designed to introduce caregiver with the knowledge and skills needed in their role as a carer to an older adult. The course topics are:

- Who are carers and what they do?
- Whom will you be caring for and the process of ageing?
- Social and emotional needs of an older adult
- How to keep an older adult and yourself as the carer safe»

B. Supporting Older Adult Personal Care & Independence

This course details the important practices associated with caregiving. It delivers online materials with instructions on how to provide assistance in bathing, showering, and use of

Partner	Type
Imperial College London	Academic
Karolinska Institutet	Academic
University of Oxford	Academic
Home Instead Senior Care	Private Sector
Abbott Nutrition Institute	Private Sector
French Institute for Research in Computer Science and Automation	Research
Sorbonne University	Academic
University of Coimbra	Academic
Ville de Nice	Public Sector
City of Stockholm	Public Sector
University of Toulouse - Gerontopole	Hospital
Global Coalition on Ageing	Private Sector
Nanyang Technological University	Academic
Research Institutes of Sweden	Research
Philips Healthcare	Private Sector
Kensington and Chelsea Social Council	Public Sector
University of Coimbra	Academic
Universitat Politècnica de València	Academic

Table 1. List of Official Partners of CARE Campus

toilet facilities. It also illustrates best practices associated with everyday assistive caregiving, from daily grooming, mobility, and support around the home and introduces best practices associated with everyday caregiving for older adults with cognitive impairments, like dementia or Alzheimer’s. The course topics are:

- The mindset of a caregiver
- Precautions for Safe Personal Care
- Assisting with Bathing and Showering
- Assisting with Use of Bathroom or Toilet Facilities
- Assisting with Hygiene and Grooming
- Assisting with Mobility, like Walking and Transfers
- Support Around the Home: Cooking, Feeding, Cleaning, and Laundry
- Personal Care for Older Adults with Cognitive Impairments

C. Age related diseases and disorders

This course explores a range of diseases, disorders, conditions, and comorbidities that older adults may encounter as they age. The course introduces age-related diseases and disorders that are common in older people. These include conditions in many parts of the body, like the nervous system, cardiovascular system, musculoskeletal system, and the urinary system.

This course introduces a series of interviews

with clinical specialists, and lead patients to help caregivers gain a deeper understanding of the common conditions that occur with age. It covers various aspects of dementias and mental health disorders. In addition, a short introduction to cardiovascular diseases, stroke, respiratory diseases and diabetes. The course topics are:

- Basic principles of age-related diseases and disorders.
- The symptoms of age-related diseases and disorders in older adults.
- The impact of age-related diseases and disorders on older persons and their relatives.
- Strategies to manage the impact of age-related diseases and disorders on older persons and their relatives.
- Polypharmacy and comorbidities associated with age-related diseases and disorders
- Best practices in the care of older people with age-related diseases and disorders.

D. Promotion of Healthy Ageing

Through this course, caregivers will learn how to promote an active and healthy ageing when caring for an older adult. The course explores lifestyle-related factors and the prevention of diseases and disorders in old age. The course focuses on explaining the key lifestyle-related factors that are modifiable and influential for the well-being of older adults such as diet, physical activity, stress management and sleep. The course topics are:

- Introduction to healthy ageing
- Lifestyle-related factors: first principles
- Lifestyle-related factors: cognitive and socioemotional aspects
- Long-term perspectives in healthy ageing

E. Caring for the Carers

This course provides key information on the role of a carer and the care relationship, the caregiving potential impact on wellbeing, quality of life but also physical and mental health of the caregiver. It delivers guidance on the way to recognize and prevent stress, but also to reduce the risk of exhaustion and social isolation. This course is intended for anyone engaged in a care relationship with older people in disability or dependency situations, whether formal or informal caregivers. The course topics are:

- Recognize the characteristics of the care relationship and the carer’s role
- Understand the potential consequences of this role on health and well being

- Reflect on strategies to prevent stress and exhaustion, and to better assume this role in preserving your life balance
- Find professional help in your own health care system and to build your own resource pack in order to maintain your role
- Rights and responsibilities of caregivers

F. Technology & Ageing

This course provides an overview about the current and future technologies that can help caregivers and the older adults in managing health related duties and activities of daily life. The course provides the basic concepts of assistive technologies for older adults and their impact on the different functions and life dimensions. It also covers some methods to help the caregiver select the appropriate tool or technology tailored to the caregiver and the older adult needs. The course topics are:

- Daily life difficulties of older adults
- Assistive Technologies for older adult people: impact on the different functions and life dimensions
- Methods for caregivers to select the appropriate tool for each older adult

G. Socio-demographic: current and future challenges

In this module, caregivers will learn about the development of the population structure and the main factors which influence it (fertility and mortality). They will also learn how this development will impact the provision and financing of health and social care and will understand the roles of families in providing care and support for older family members. The course topics are:

- An introduction to population change.
- What is happening to our levels of fertility (childbearing)?
- Will we continue to live longer and longer?
- The implications of population change as described in the first three sections for the financing and provision of health and social care and the role of families in providing care and support for older family members.

H. Nutrition in Ageing

Diet is essential in preserving overall health and caregivers can play a vital role in supporting older people's nutritional needs. This course provides information about nutrition and dietary requirements towards healthy ageing, prevention

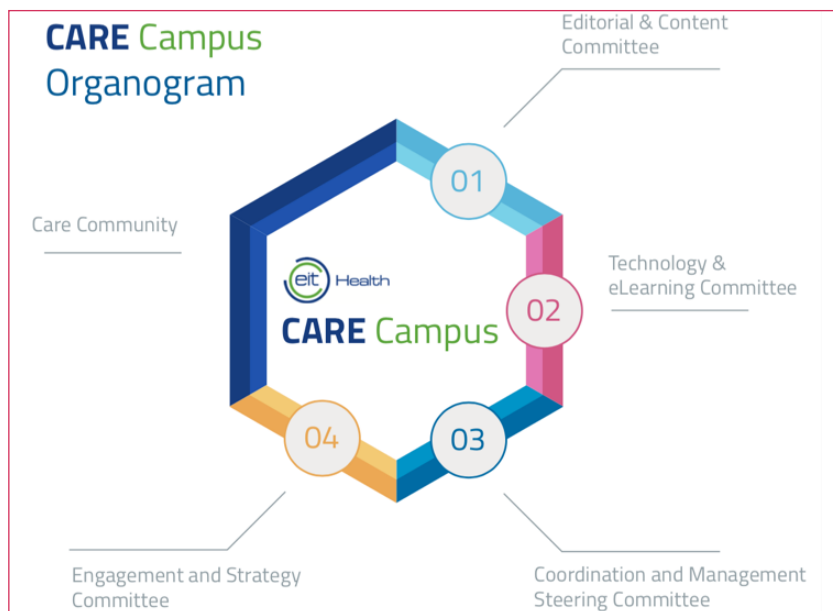


Figure 1

of age-related diseases, such as dementia and cardio-vascular diseases, the impact of social settings on eating behaviors and accessing community resources. The course syllabus includes:

- Nutrition and the Lifecycle
- Nutrition and Disease prevention
- Malnutrition and Dehydration
- Muscle Mass and Eating Behaviours
- Carers and the Community

This course has been co-designed and co-delivered by a multidisciplinary team including nutrition experts, primary care physicians, social workers and carers.

I. CARE: Caring at End of Life

This course is a useful tool for anyone with an interest in caring for older people as they become frailer and approach the end of life.

Caring for an older person towards the end of life is not easy. With this in mind, a five-part interactive course on caring for older people has been developed. The course covers important questions related to end of life, the common symptoms and problems of the end of life, the types of practical care most frequently needed for a person at this point of life. It also covers the needs right before and right after the person dies and grievance.

Curriculum Validation

The entire curriculum as well as each course goes through a strict and systematic quality assurance process that has been designed and is continuously assessed by an independent committee within CARE Campus: Educational Review Committee [figure 1]. This is achieved by following an active evaluation approach using (1) co-design/co-production during the design phase, (2) qualitative/quantitative post-delivery assessment of the competencies and skills gained, and (3) big data learning analytics using the data collected from the first learning programme of CARE.

1. Design Stage

Co-production: This phase involves the caregivers' community as co-designers. This approach ensures the alignment of the learning outcomes to the actual need of the community and the inclusion of an element of reciprocity between the caregivers, the elderly, the family, and the experts of CARE Campus to build a sustainable model to training and support. Several co-production sessions have been launched with partners in France, UK, and Sweden. The co-production helped assess whether the content was relevant to the caregivers and more importantly whether it was culturally aligned.

2. Post Release Evaluation:

Online Questionnaire: Following the release of CARE Campus training program, an evaluation questionnaire will be released to participants who will be randomly selected. The questionnaire will collect and analyze the information for and about the training program. The results will be used for planning and guiding decision-making as well as assessing the relevance, effectiveness, and the impact of various training components. It will be carried by researchers in the core academic institutions in partnership with the local NGOs of carers.

Big Data Learning Analytics: the new approaches to online learning such as Massive Open Online Courses (MOOCs) offer an unprecedented approach to embed big data "learning" analytics into the evaluation process of the program. Imperial College will lead this initiative, which will analyse the trove of data collected from the EdX platform to inform, evaluate, and validate the Course, reading to its future development, optimization and updating.

Challenges

CARE Campus faces several challenges that span across different domains. First and foremost, the CARE Campus curriculum is designed to be inclusive and support all caregivers across Europe independently from race, religion, social backgrounds, or culture. It is important that all materials are meticulously validated and adapted to all backgrounds and are compatible with individual, local and national diversities. While this may be very difficult to achieve, it is an important component when we explore expanding our programme and offering. In addition, while digital technologies are becoming widely available to all people, relying on a digital delivery of our programme represents a limitation of itself. In 2019, we are exploring with our partner Ville de Nice a hybrid model of training programme which combines online training with on-site training. Our aspiration is that the CARE Course will stimulate other public and private initiatives across Europe that will further support the growth of a well-trained work force, in line with the guiding principles of EIT.

Second, Innovation in healthcare delivery is hard. CARE Campus is still an early stage experiment. Although it includes several partners, it is predominantly supported through the EIT Health educational funds. In that respect, CARE Campus long term impact will be dependent upon a sound sustainability plan. The consortium is exploring several models and partnerships.

Lastly, Europe still lacks a legal framework governing caregiving, including rights and responsibilities and qualifications and training requirements. As CARE Campus projects to deliver a European certification and accreditation programme, we hope that we will contribute to the development of such a framework in the non-distant future. A pan-European strategy for caregiving is the most pressing issue at hand today which must be tackled as a matter of urgency.

Conclusion

CARE CAMPUS aims to provide the foundation of a comprehensive and validated educational and training platform for caregivers for all settings, including home care and traditional institutional care. Thus, in addition to being a value contribution for senior care across Europe and jobs creator, CARE will also improve productivity for employed family caregivers, enhance sustainability of healthcare systems and

lead to economic growth across Europe. This will benefit our ageing citizens themselves, family caregivers, and society, by reducing the burden on health care systems, whilst improving the quality of care for our citizens. It is a unique model of collaboration between academic institutions, private and public sectors across Europe.

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