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CAREPATH: Developing Digital Integrated Care Solutions for Multimorbid Patients with Dementia

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Abstract. CAREPATH project is focusing on providing an integrated solution for sustainable care for multimorbid elderly patients with dementia or mild cognitive impairment. The project has a digitally enhanced integrated patient-centered care approach clinical decision and associated intelligent tools with the aim to increase patients' independence, quality of life and intrinsic capacity. In this paper, the conceptual aspects of the CAREPATH project, in terms of technical and clinical requirements and considerations, are presented.

Keywords. Clinical Decision Support System, Multimorbidity, Dementia

1. Introduction

In the last decade, development of Clinical Decision Support Systems (CDSSs) has become popular in the health informatics domain[1]. Implementation of CDSS in daily

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medical practices is believed to improve healthcare providers' performance on clinical decision-making, quality of care and patient safety, although there has been disadvantages and limitations in their clinical implications[1]. Meanwhile, healthcare providers face challenges in conciliating recommended tasks and activities of different guidelines in multimorbid patients[2]. The heterogeneity of patients accompanied by the complex nature of their health condition makes the existing guidelines, with disease-oriented approaches incapable of providing the same level of improved patient outcomes in this group of patients[3]. This has highlighted the importance of patient-specific recommendations for multimorbid patients, which are frequently provided through computer-interpretable guidelines (CIGs) [5].

Such multimorbid conditions can be demonstrated in diagnosis and management of dementia, where most guidelines have focused on managing dementia as a single disease [5]. The existing guidelines have been developed to provide the necessary advice on supporting people with dementia and their caregivers in health and social care, without holistic consideration of their implications on other morbidities and intrinsic capacity of the patient. At the level of "best practice", we are facing increased challenges and difficulties in the use of good clinical guidelines due to the co-existence of dementia with other morbidities [6]. These challenges can include but are not limited to polypharmacy, adverse drug reactions, and frequent non-adherence to treatments [3].

In Europe, the single-disease oriented health system and ageing population, which increases the risk of multimorbidity [7], has affected healthcare costs and efficacy and the sustainability of health systems [8]. When dementia is present, the situation becomes even more complicated [6]. The CAREPATH project is a research project within Horizon 2020 that focuses on the enhancement of healthcare interventions for the management of elderly multimorbid patients suffering from dementia. It aims at developing ICT solutions with integrated patient-centered approaches to care for patients with multimorbidity to increase their independence, quality of life and intrinsic capacity (9). In this paper, we are discussing the conceptual aspects of the CAREPATH project in terms of technical and clinical requirements and considerations.

2. The Holistic CAREPATH Solution

CAREPATH will provide a holistic environment that efficiently addresses multimorbidity and dementia challenge in the elderly population, by delivering three complementary components: (A) A Home and Health Monitoring platform implemented at the patients' homes integrated with Advanced Early Warning Smart Decision Tools, providing environment aware services with natural and comfortable interfaces for older adults for continuously collecting real time data for early detection of onset and changes in functioning, autonomy, underlying cognitive and physiological functions and to derive dementia profiles and intrinsic capacity of these patients, (B) A Patient Empowerment Platform providing personalized assistance to the patients, guidance and reminders about care plan goals and activities, present educational materials for reinforcing treatment adherence; collect feedback from the patients and their informal caregivers via PROMs for carrying out geriatric assessments and (C) An Adaptive Integrated Care Platform for health professionals, enabling implementation of adaptive care plans based on evidence from clinical guidelines, but prioritizing and reconciling them with the help of clinical decision support systems, processing patient's most recent context from the home monitoring environment and Electronic

Health Records for calculating risk scores for comorbidities and monitor disease progression and intervention effects and tackling polypharmacy management.

3. Steps for developing integrated patient-centered solutions

Team building: It is of crucial importance to identify and build partnerships with all stakeholders in the CDSS domain. For the CAREPATH project, a consortium is composed of ten organizations (universities, clinical organizations, and SMEs) from six countries (Germany, Romania, Spain, Switzerland, Turkey and UK). The team members have expertise in clinical, technical, health economic and ethical aspects relevant to the project. The clinical investigations will be carried out in Germany, Romania, Spain and UK, four countries with diverse health and social care systems.

Clinical Aspects: The clinical teams are expected to provide patient-centered best practice guidelines based on existing evidence, reviews, legislations, and expert consensus. They should also develop or approve the polypharmacy management services to be implemented in the CDSS. Clinical teams will also support collecting the user requirements and determine characteristics of various target users, as well as instrument specifications in the clinical setting. Finally, a clinical investigation phase will be conducted for system validation and improvement.

Technical Aspects: The main task expected from the technical team is to design and introduce a generic reusable architecture. This holistic, cross-sectoral and interdisciplinary patient-centered care model of personalized care services is built on existing prototypes of IONIS, C3-Cloud and imergo®-ICP (10). The system is intended to provide patients, healthcare providers and caregivers with smart early warning CDS services and home and health monitoring capability. The prototype will be evaluated by a technical validation and usability study. Feedback from each phase will be provided to the technical team for further improvements. There will be critical security and privacy issues to be dealt with during this process to help patients and caregivers better manage health related conditions. Finally, the integrated care solution would be presented in accordance with present standards such as HL7/FHIR, using comprehensive, multilingual clinical healthcare terminologies e.g., SNOMED. The functions will be performed by means of APIs for exchanging electronic health record based on CDS Hooks specification for describing the RESTful APIs and interactions to integrate Clinical Decision Support (CDS) between CDS Clients and CDS Services.

Economic and Ethical Aspects: A Health economic study and analysis is an important part of this project. The acceptability and sustainability of the project is partially determined by the success of adjustments made based on the findings of the health economic studies. The project endures important ethical considerations. An ethical team is required to participate in all phases of the development process to ensure all requirements are met.

4. Concluding Remarks

The health and social needs of ageing populations are often complex and ongoing, spanning a range of areas of functioning and fluctuating over time. Traditional care models for people in later life are frequently fragmented and inefficient [11]. Even in countries with reasonably well-developed health and social care provision, treatment of

dementia patients with multimorbidity is generally provided without careful monitoring of the current intrinsic capacity and dementia profile of the patient. There is a need to employ fundamental changes to the focus of clinical care for older people from treating specific symptoms in a disjointed fashion to adapting holistic approaches according to older people's physical and mental capacities. CAREPATH will follow an integrated patient-centered approach, in order to develop a flexible and modular system that will provide a viable solution for improving the management of multimorbid elderly patients with dementia and possibly improving intrinsic capacity, by delivering a system of care adapted to their needs.

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