

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) patients' engagement in outcome measuring and disease management through Information Technology

Diana Araja¹, Uldis Berkis¹, Jesus Castro², Andrejs Ivanovs¹, Angelika Krumina¹, Asja Lunga¹, Modra Murovska¹, Simons Svirskis¹, Pawel Zalewski³ (1) Riga Stradins University, Latvia, (2) Vall d'Hebron University Hospital (VHIR), Spain (3) Nicolaus Copernicus University in Torun Collegium Medicum in Bydgoszcz, Poland

Introduction

There are no Europe-wide prevalence data, but it is assumed that more than two million people suffer by Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) in Europe. Symptomatology, severity and disease progression are extremely variable, and illness most commonly occurs between the ages of 20 to 50, that significantly impacts the labour productivity. Given the topicality of this item, the group of researchers from 11 European countries had initiated a project to establish a communication network to support research on ME/CFS and improve patient engagement. The project was successfully implemented as the COST Action 15111 EUROMENE (ME/CFS Research Network). The main ME/CFS Working Groups' topics were following: epidemiology, biomarkers, socio-economics, and clinical research.

Results

Descriptive statistical analysis of the study has shown the data differences between countries (published at the separate issue), but the current issue is mostly dedicated to the patients' reported problems, which should be solved:

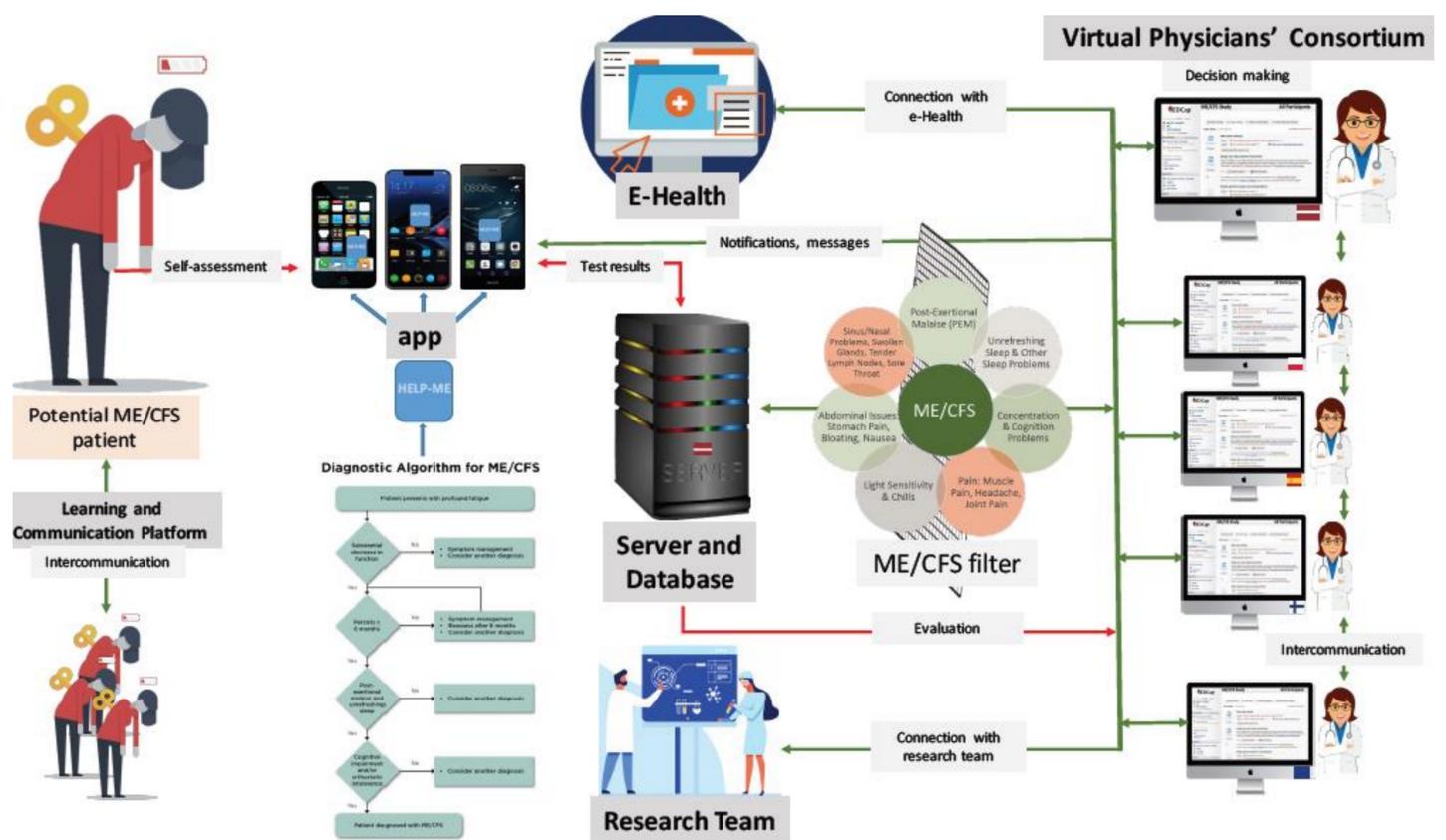
(1) in most cases, patients claimed that therapies had a slight or a null effectiveness, which suggests that more effective treatment navigation is required to provide patients with therapeutic answers;

(2) to be noticed that the largest part of patients had difficulties in explaining the disease to their doctor, and only half of patients' number stated that they can rely on their general practitioner in the future;

(3) to this extent, it also arises the need for a personalized therapeutic path, which should be supported by a strong relationship between patients and doctors, patient self-awareness and new technological solutions for disease management.

Methods

To achieve the objectives of EUROMENE socio-economics research, a study based on the patient-reported survey has been carried out in three of the project's countries. The survey included questions concerning the socio-economic consequences of the disease, particularly regard to health care costs, the loss of productivity, and the limitations in daily life, using EuroQol-5D as a generic measure of health status. For data processing and analysis, the methods of economic analysis and statistical analysis are embraced.



Conclusions

Taking into account the identified challenges accompanied the process of collecting Patients Reported Outcomes (PROs) in case of ME/CFS disease EUROMENE member countries' representatives have defined a view on creation of App and web platform for ME/CFS patients' self-empowerment and disease management, where the target users are people suffering from ME/CFS, and practical challenge is diagnosis, stratification and monitoring of ME/CFS at the level of general practitioner (GP), supported by the virtual doctors' consortium, as well as patient self-awareness and proper practical navigation in the healthcare system (Figure).

Based on the joint view, the Riga Stradins University (Latvia) has submitted the project proposal to EU ERDF 1.1.1.1. programme. The objectives of the proposal are defined as following: 1) patient-centred, societally oriented, real-time decision-making using the PROs; 2) using artificial intelligence to support the decision-making on patient and treatment pathway; 3) learning opportunities for patients, caregivers and health professionals. The outputs of this initiative can be used to develop the ICHOM standard sets for ME/CFS disease and improve the outcomes measuring.

Objectives of the study are related to activities of the ERDF project 1.1.1.5/18/I/011, VPP-COVID-2020/1-0023 and LZP-2019/1-0380.