Usefulness and Importance of Informatics Solution in Evaluating Disability - Starting Point for Physical and Rehabilitation Medicine - Draft Application

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INTRODUCTION

Disability is one of the paramount concerns among non-communicable diseases identified by the World Health Organization (WHO) post-2015 agenda (1). Nowadays, disability is recognized as an important but neglected by public-health concern (2). The definition of disability has been a reason to debate among specialists in the medical and social science fields for decades (3). In 2001, the World Health Organization (WHO) published the International Classification of Functioning, Disability, and Health (ICF), which promotes a new vision of health and disability and defines the latter as a “difficulty in functioning at the body, person, or societal levels, in one or more life domains, as experienced by an individual with a health condition in interaction with contextual factors” (4).

The International Society for Physical and Rehabilitation Medicine (ISPRM) defines its role as the world’s direct association in the field of rehabilitation medicine. Consequently, ISPRM defines its mission and aim not only at “the improvement of knowledge, skills and attitudes of physicians”, but also “to help improve quality of life for people with impairments and disabilities” as well to “facilitate rehabilitation medicine input to international health organizations (…)”. This includes the goal “to influence rehabilitation policies and activities of international organizations interested in the analysis of functional capacity and improvement of the individual quality of life (…)”. Since 1999 ISPRM has been in official relation with the World Health Organization (WHO) and their purpose together, for the period of 2011-2013, was to establish several subcommittees in order to be able to fulfil the
a sets of tasks and to ensure a continuous input at the highest possible level. The topics of the collaboration plan are: the “Strengthening Medical Rehabilitation”; the “Implementation of the International Classification of Functioning, Disability and Health”; the “Community Based Rehabilitation”(6). The crowning work of the WHO was the launch of the World Report on Disability in June 2011, translated into Romanian language in September 2012 by Romanian Society of PRM.

Starting from the ideas above it was thought that creating an informatics solution to evaluate disability is not only necessary, but also imposed by the trends and life that we are living.

About disability and PRM

Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity. WHO tells us that “disability is an umbrella term, covering impairment, activity limitations and participation restrictions”. “Impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations. Disability is thus not just a health problem. It is a complex phenomenon reflecting the interaction between features of a person’s body and features of the society in which he or she lives. Overcoming the difficulties faced by people with disabilities requires interventions to remove environmental and social barriers” (7).

Over a billion people live with some form of disability. This corresponds to about 15% of the world’s population. 110 million to 190 million adults have very significant difficulties in functioning. Rates of disability are increasing, due to population ageing and the global increase in chronic health conditions.

In Romania according to the report given in September 2014 by Ministry of Labour, Family and Social Protection there are more than 720,000 persons with a form of disability (8.3% children and 91.7 adults) rising with 44% compared to year 2000 and with 2.4% compared to last year. It can be said that 3.5% of Romanian population have a disability and more than 40% among them has a physical or chronic impairment. Only 4% of persons with disability (1% physical disability, 1.8% chronic disease) are employed according the same report. European Union Labour force survey puts Romania on the highest inactivity rates for persons with disabilities in Europa along with Hungary, Bulgaria and Ireland.

Accessibility to surrounding world is fundamental for people with disabilities. Accessibility means the right to the education you want to follow, choose a career or enjoy life in any way you want. Access is made via methods, techniques and flexibility in educational curricula, by ramps with correct angle, by placing audio for the blind in the streets and buildings, light signals for the deaf or by using the icons in all public areas. Accessibility can be viewed as the “ability to access” and not to be confused with usability. This is why European Union through “European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe” focuses on eliminating barriers. The Commission has identified eight main areas for action: accessibility, participation, equality, employment, education and training, social protection, health and external action.

In The World Report on Disability (WRD) a full chapter is dedicated to rehabilitation and physical and rehabilitation medicine (PRM). WRD stresses that, in order to achieve its goals, it has to put PRM in centre of the plan because it has a major importance and an important contribution to enhance a person’s functioning and participation in life (8). Rehabilitation is an active, time-limited collaboration of a person with disabilities and professionals, along with other relevant people to produce sustained reductions in the impact of disease and disability on daily life. Interventions focus on the individual, on the physical or social environment or on a combination of these (9).

E-Health

Electronic Health Record (EHR) is a systematic collection of electronic health information about an individual patient or population. Modern EHR systems are commonly composed of more than just patients related data collections; it is a development area of resources to incorporate all team members into practice to amend patients care and health outcome (10). They also include solutions to assess treatment, such as clinical decision strategy, medication management and complex evaluation (11).

Goal of EHR. The primary purpose of the EHR is to provide a documented record of care that supports present and future care by the
same or other clinicians. This documentation provides a means of communication among clinicians contributing to the patient’s care. The primary beneficiaries are the patient and the clinician (12). Secondary use are: research – development and evaluation of new diagnostic modalities, disease prevention measures and treatments, epidemiological studies, population health analysis (13); health service management and cost saving – resource allocation and management, cost management, reports and publications, marketing strategies, enterprise risk management and also education (12); improve health care - efficiency of health services delivery, time savings for all health professionals and patients generally (14); less clinical and medical errors associated with inadequate or incomplete information, improvements in public health (evidence has shown that computerized decision support systems can improve patient safety) (15,16); improved quality of care and patient safety - computer-based clinical decision support systems demonstrated a beneficial, though variable, impact on physician performance in 43 out of 65 studies - 66%, and a beneficial effect on patient outcomes in 6 out of 14 studies - 43%(17,18); policy development – health statistics analysis, trends analysis, case mix analysis (19).

Internet infrastructure enables the user to access any kind of information anytime from anywhere. It can be said that e-health is based on EHR. Reviewing the definition of the term and the concept of e-health on Medline database the most relevant one is: “e-health is an emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies. In a broader sense, the term characterizes not only a technical development, but also a state-of-mind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology” (20).

Goal of e-Health. From an overall perspective, e-Health can be used to provide that the most current information is used to amend people’s health and also to disseminate health information (21). Additional purposes are: increased efficiency in health care, improved quality of care; increased commitment to evidence-based medicine; empowerment of patients and consumers; development of new relationships between patients and health professionals (22).

Informatics solution- draft application

The last decade registered the expansion of Internet as the main modality of communication. The most inciting subjects in the field of health refer to adopting the information and communication technologies solutions in the whole health system by implementing and developing an application that is proved to be efficient and usable.

The idea of accomplish a database for assessing disability is not new (23). The Minister of Health started in 2010 a National Program that active monitor the patients with ambulation disabilities (adults and children) but until now there are no results of regarding this agenda. In Romania such an application would be a first step for PRM physicians to see patients from the same perspective and learn to “speak the same language”. Most of the applications evaluate health condition of the population or disability in whole levels. The concept of developing a disability survey application has been practiced in European Union countries such as Italy, France, Ireland, Spain, Portugal, Turkey, United Kingdom (24). From the searches on MEDLINE and Repository of Disability Surveys and Censuses the existence of an application which evaluates the population who is disabled by major diseases of the neurological-muscular-articular systems has not been done so far.

A healthy population relays at the basis of economic growth and community prosperity. The starting points in developing the informatics solution are:

- The International Classification of Functioning, Disability and Health (ICF) how is an evolution in the concept of disability measurement. It explores disability as an outcome of interactions between a person with a health condition and various environmental and personal factors, rather than focusing only on a person’s health or impairments (4).
- The axioms that given by WHO: nationwide relevance and standardization of an evaluation is essential (incorporated into other national surveys), the questionnaire has to include beside the eva-
There will be enrolled 4 medical relevant centers. Every medical center can have this way an accurate statistic regarding the number of persons with any kind of disability, the evolution status of every person related to his disability. It also gives a real time reporting, a fast and accurate report, a case follow-up, a faster and a clearer management.

Security/Privacy. Any security issues must be resolved while designing the healthcare applications or else they may give rise to serious social problems. In light of modern concepts of security, the safety should accompany the availability, efficiency and the quality parameters of the information. Therefore the system and information security threats should include all aspects of the network and its applications (24).

The security of the IT application is given by: data encryption - the data is encrypted so that it is not disclosed whilst in transit. Data encryption service provides confidentiality against eavesdropping attacks; data integrity - it is an efficient method against data modification attacks; authentication - every user of the project will be given an user name and a password; privacy - there will be only few users of the data: the physicians, nurses and some other clinical/technical staffs. This limits the number of users in the system so gives a better privacy (25); The application is stored on a dedicated server which will hold only this application avoiding this way all the vulnerabilities which could be generated if other applications will also stored on the same machine.

Structure. Any person who will address to one of the four rehabilitation centres could be introduced in the survey. The purpose of the study and the examination procedure were explained to the subjects and verbal consent was obtained before examination. A standard protocol will be used to register the patients. It will be retained the demographic information so any person could be identified easily and also for adding a new evaluation charge to be done at any next presentation.

The examination protocol will include:

A standard interview and an evaluation form completed by the physician. This will include the following sections: diagnosis - an algorithm was used to give a specific diagnosis for each person, a diagnosis that fits best his disability but also do not miss any disease condition; cognitive state by using Mini-mental...
State Examination); environmental facilitators and barriers using ICF set cores; the evaluation of the severity of patient’s disability and quantifying the results in “a uniform way” using FIM instrument and comparing the results for ADL with Barthel Index for determining the validity and usability for the Romanian people; level of ambulation (26); patient categories (27).

An evaluation questioner completed by the patient about health condition, life expectations, environmental and social barriers.

RESULTS

The strength of this data base is that a nationally representative sample of people of all ages was enumerated and examined. The information will not be put under the human error or subjectivity. It will be used a sensitive screening tool, a robust questionnaire and examination protocol, and not last there will be determined and follow-up needed of assisted device. The results will be easily compared with linked studies because all the involved scales in the evaluation have already demonstrated efficiency worldwide. The data gathered by the IT solution will be submitted to a statistical research so it can be established its validity, reliability and freedom from gross or relative bias, sensitivity and consistency over time and portability.

In the end the last goal is to try linking all the information to the hospital’s software in order to be adopted and used easily by all clinicians.

CONCLUSIONS

The PRM field can successfully use the benefits of the information technology to accomplish the main goal which is to have a generic manner to evaluate the disability in Romania.

The system-concept offers a unique solution in determining the dimension of disability across Romania and hopefully the impact that the disability has nationwide. With this IT solution it is wanted to outperform the existing systems and, after, if it will prove its value as a research tool, to be used as an online processing instrument able to provide convenient, efficient, and effective data.

A preliminary version of the system is fully implemented and after the user are trained they will start introducing data. This technology was thought to assist medical practitioners/researchers by enabling efficient management and sharing of the medical data within or across a community without being subject to geographical restrictions and without creating problems of inconsistent and fragmented medical data. In the end it is hoped that this program will be a decision support tool and also will allow the clinicians, to have standards that will constitute evidence based arguments for the political decision makers to improve quality of life to the people with disability according the document that the Romanian Government has signed with EU and WHO.

The IT solution is at this moment in its final stage of drafting so a future article with the obtained results will be published.

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