

Physical and rehabilitation medicine in the XXI century: challenges and opportunities

A medicina física e reabilitação no século XXI: desafio e oportunidades

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ABSTRACT

This paper addresses some of the issues that are shaping rehabilitation nowadays, such as changes in demographics and epidemiology of diseases, raising patients' expectations, increasing costs of rehabilitation care and also the difficulties in establishing boundaries between PMR, other medical specialties and rehabilitation professionals. Some contextual changes which have occurred in the last years in concepts, mentalities and policies related to disability and rehabilitation will be pointed out, as well as the benefits of technological evolution as a tool for enhancing social inclusion of people with disabilities. The recently created network for continued and integrated care, which is being set up in Portugal, will be referred, as a response to the need of providing integrated services. These changes may represent opportunities to enlarge PMR field of intervention and to confirm its role on promoting social understandings of disability. Finally, some new perspectives for rehabilitation on the edge of the 21st are suggested.

Keywords: Disabled Persons, Physical Medicine, Public Police

RESUMO

Neste trabalho efetua-se uma reflexão sobre algumas das questões que estão a influenciar a reabilitação na atualidade. As alterações demográficas e a epidemiologia das doenças, o aumento das expectativas dos doentes, o crescimento dos custos dos cuidados de reabilitação, e também a dificuldade em estabelecer os limites entre a MFR, as outras especialidades médicas e outros profissionais de saúde, são alguns dos desafios da nossa prática diária. Por outro lado, as mudanças nos conceitos, mentalidades e políticas relacionadas com a deficiência tal como a evolução tecnológica, são oportunidades para alargar o campo de intervenção da Medicina de Reabilitação, confirmando o seu papel decisivo na promoção do entendimento social sobre a deficiência. Finalmente, abordam-se algumas novas perspectivas para a reabilitação no século XXI.

Palavras-chave: Pessoas com Deficiência, Medicina Física, Políticas Públicas

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Doi: 10.11606/issn.2317-0190.v17i1a103310

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INTRODUCTION

Rehabilitation Medicine arose about 60 years ago, to provide care for disabled people and to promote a normal and a fruitful life to them, as possible. The specialty had already a holistic view of the individual, considering not only the physical aspects of his condition but also the social and psychological problems that could interfere with the patient's recovery.

In the last decades, the remarkable evolution of science determined profound changes in society, affecting all domains of life. However, not all areas of intervention were able to adequately and quickly adjust to these rapid changes. Today, healthcare systems are facing various challenges that require a change in concepts, models of functioning and management of organisations in order to guarantee access to healthcare, maintaining simultaneously a high level of quality and ensuring financial viability. These are complex problems with no easy solutions. Rehabilitation services, being included in the healthcare system, also suffer these pressures to change.

Demographics

Ageing of society is a common feature that is becoming more apparent in most developed countries. This phenomenon presents a challenge to various sectors (health, social security, and the labour market), thus implying a shift, in certain cases almost radical, of the needs and the politics. Hospitals and services will have to be adjusted and reorganised.

In the last two decades, Portugal has grown older: the population 65 and over went from 10% to 15%.¹ This corresponds to an increase of almost 50%. To this fact contributed not only the rise in life expectancy (+11% for males and +7% for females) but also the decreased of the birth rate (-26%).

It is also well known that, as populations grow older, the proportion of women tend to increase. Although this phenomenon is perhaps becoming less apparent, as life expectancy of males tends to come closer to those of women in western industrialized nations, it's still significant and raises important issues for clinical practice. It is quite different to discharge an aged male patient who just had a stroke and who has at home a dedicated wife to help and care for him, than to discharge a female patient of the same age, whose husband has never performed such roles in the household before.

Population ageing has two important consequences: first, it is strongly correlated with disability, mostly due to natural degenerative pro-

cesses and deteriorating health; secondly, it puts pressure on societies and particularly on health and welfare systems, to care for this group. Both are likely to shape the ways in which we organise and provide rehabilitation services.

Epidemiology of Diseases

The second point is about the changes in the reality and pattern of disease.

A substantial proportion of the population – up to half the population in the USA and almost 40% in the UK have a chronic condition and many have more than one. Part of this phenomenon is related to the ageing of population, which we have just mentioned.

Also, the remarkable advances in technology and Medicine have allowed people with severe disabilities to survive; these people will also benefit from the longer life expectancy of the general population.

People most severely disabled, the majority of them experiencing neurological damage and complex disabilities resulting from a combination of physical, cognitive, and behavioural impairments^{2,3} require differentiated healthcare services which are very expensive. In the USA, for example, this group accounts for nearly 80% of healthcare costs.⁴

Hospitals are still structured for treating acute illnesses (rehabilitation services are among the few specialties that have traditionally focused on chronic patients), although increasingly the majority of cases seen in hospitals require long term care. Such disparity between what patients need and what providers are able to deliver, causes a feeling of frustration on both sides. New models of treatment and care need to be developed to adequately respond to these challenges.

Dependency on daily activities implies having people specially trained to provide that care and money to pay for it. Family is a key element in the process of rehabilitation, being the first provider of care. Having to care for many years for a dependent person is a very arduous and demanding task. Most of these families are wearied because caring for a dependent person implies a continuum adjustment of attitudes and behaviours, sometimes even deep shifts in family roles.

Adding to these social issues, come also important economical challenges; frequently, the need to provide permanent assistance to a relative implies quitting the job, placing another burden on the family.

As chronic diseases and long term dependency raise families are ever more requested to perform the role of care givers. This happens mainly for two reasons: on one hand, to keep the individual in his natural environment, and on the

other hand, for better resource management.

So, it's not surprising that most of these families are suffering from what is called "family burn out". The rehabilitation team has an important role to play - teaching these families how to take care of a person with disability and also, as important as that, understanding the difficulties families face in order to point out some options.

Patients' Expectations

The third point is the growth of a more demanding public, who find that hospitals are much more disorganized and unresponsive than many other services that they use. We need to be aware of this, particularly because most of our patients having chronic conditions use the Hospital repeatedly.

They are also more informed about their condition than they used to be, due to an easier access to information. Usually, by the time they see a Psychiatrist, especially young patients who suffered spinal cord injury, they have already read all about their condition on the internet. While not all the information available on the net is accurate and patients still need to be elucidated about their particular case, this contributes to changing the patient-doctor relationship.

Patients expect more of the health system/hospital and demand the right to choose. The concept of choice, which has been inherent in the rehabilitation process since its inception, has evolved into legal mandates and ethical challenges for rehabilitation professionals during the latter part of the 20th century.

It is a process that is based upon access to, and full understanding of all necessary information from the patient's perspective. The process should result in a free and informed decision by the individual about whether or not s/he desires to obtain health services and, if so, what method or procedure s/he will choose and consent to receive.

Rehabilitation services should no longer be imposed without the consent and participation of people who are using the services. This is also the viewpoint put forward by the World Health Organization. In a recent report,⁵ the organization considers rehabilitation as a process in which people with disabilities make decisions about what services they need, to enhance participation. According to this perspective, professionals who provide rehabilitation services have the responsibility to present relevant information to people so that they can make informed decisions regarding what is appropriate for them. This new model of service provision again contributes to shaping new patient-doctor relationships.

Rising Costs of Rehabilitation Care

Another challenge to the present context relates to increasing healthcare costs. The percentage of GDP (gross domestic product) spent in healthcare is growing. For instance in Portugal, the GDP has risen 2.3% per year from 1990 to 2001; however the percentage of health expenditures rose 6.1%. This trend is expected to continue in the future. According to data from the OECD, public spending on health and long-term care could rise from the current average level of 6-7 % of GDP to around 10% by 2050 (an increase of over 50 %).

Population ageing, demanding more healthcare, and the ongoing technological evolution consuming more resources, will eventually lead health systems to a situation of economic unsustainability. That has made the governments to be careful and to use every available tool to trying to limit healthcare expenses. However, it hasn't been easy and the health expenditures have continued to grow above inflation.

In Portugal, while a universal healthcare system still survives, in recent years the private sector has increased its share in the provision of healthcare through the raise of managed care systems and the establishment of public-private-partnerships. In consequence, gradually, a new paradigm of healthcare management is arising, involving profound transformations in models of funding, management and operation of healthcare services.

Physicians are under increasing pressure to fulfil their role, facing conflicting demands from patients and administrations. It is still necessary to find a balance between an economical view and a more humanistic perspective.

PMR and Other Professions

The composition of the "rehabilitation team" will probably undertake changes as the cost of treating long-term disabilities increases, and technology is becoming more prominent. New professional skills are required to provide care for a changing target population.

The team may have to open to the contributions of other professionals like informatics, rehabilitation engineers, among others, to help taking the most advantage of technology, and also of less qualified personnel to provide assistance in daily life activities.

While the inclusion of new professionals seems important, our specialty needs to create a greater awareness of PMR services among hospital administrations and managed care directors. This can be done by proving that physiatry offers the most cost-effective meth-

od to treat medical problems like stroke and low-back pain. It can also be done by showing that rehabilitation contributes to decrease dependency costs. Research is needed in the measurement of outcomes to demonstrate the value and benefits of rehabilitation programs.

There is not enough differentiation between PMR and other professions. The term physical therapy is used countless times by both physicians and patients when referring to physiatry. According to HJ Flax,⁶ the physiatrist must make the general public and medical colleagues aware of the differences in the profession and the benefits of physiatry.

Physiatrist is the professional specially trained in the holistic approach to complete medical care of people with disabilities. Physiatrists must care for a wide range of patients, from the young in paediatric age to the very old in the geriatric group. So we are ready to face the ageing population challenge.

Physiatrists are in contact with many different medical and surgical specialists and other health professionals. In fact, we are the ones who follow the person throughout life and who establish links with other medical specialists or health professionals whenever necessary. Some authors claim that physiatry is the primary care for people with disabilities.

Rehabilitation is undoubtedly teamwork; as any other team needs leadership. From what is said above, Physiatrists are in a privileged position to assume this role. The broad scope of the specialty makes it ever more needed to complement other clinical specialties as well as to interface with the multiple and partial interventions of a number of health professionals.

Changes of Concepts and Models Towards Disability

In 1993, the UN approved the *Standard Rules of Equalization of Opportunities*,⁷ which was an important tool for rising awareness about disability rights; although not legally binding, they encouraged Governments to take action and develop disability-friendly policies. Following these concepts there has been a change in the perception of disability that has been reflected on new approaches and new models of intervention.

The clinical model was based on a direct relationship between disease, impairment, disability and handicap; the physical and/or mentally limitations where determinant for the disability. Consequently, the problem of disability was perceived within the individual with the impairment and all the rehabilitation efforts were directed to repair or fix that individual or problem in order to bring him the closest possible to the pattern of normalcy.

In 1981 the WHO proposed the following definition: rehabilitation aim[s] at reducing the impact of disabling and handicapped conditions, and at enabling the disabled and handicapped to achieve social integration ... at training the disabled and handicapped persons to adjust to their environment.⁸

Mostly through the struggle of people with disabilities and their organizations gradually a new concept of disability emerged – the bio-psycho-social model of disability, which brought about an increased awareness about the impact of environmental barriers on participation for disabled people. According to this new model, the causes of disability are no longer located in the individual but in the relationship of the person with her/his environment.

The *International Classification of Functioning, Disability and Health (ICF)*⁹ includes body structure and function, but also focuses on 'activities' and 'participation' from both the individual and the societal perspective. The ICF also includes five environmental factors that can limit activities or restrict participation: products and technology, natural environment and human-made changes to it, support and relationships, attitudes and services, systems and policies.

Experience has demonstrated that social and environmental barriers are much more restrictive to the development of the individual and the society than the particular physical conditions of those individuals.

This presents a change in the perception of disability which has important effects in all domains, namely in policies.

Changes of Policies

Accessibility is perhaps the most important issue to address in any strategy referring to disability. Accessibility refers to the need of assuring the right to participate fully and equally in all levels of daily life, including work, education, sports, culture and leisure. Equality of opportunity is the objective of the European Union's long-term strategy on disability, which aims to enable disabled people to enjoy their right to dignity, equal treatment, independent living and participation in society.

Actions undertaken by the European Union both underpin the set of common EU economic and social values by enabling disabled people to fulfil their capabilities and participate in society and the economy.

The European Union strategy is built on three pillars:

1. anti-discrimination legislation and measures, which provide access to individual rights;

2. eliminating barriers in the environment that prevent disabled people from exercising their abilities, and;
3. mainstreaming disability issues, which is the strategy of integrating issues concerning disability in the broad range of Community policies.

These strategy is somehow similar than the one followed for gender issues, which has been in practice for some years.

The European Union Disability Action Plan (DAP) 2004 – 2010¹⁰ established by the European Commission to ensure a coherent policy follow-up to the European Year of Disabled people (2003) in the enlarged Europe – provides a dynamic framework to develop the EU disability strategy with special focus on mainstreaming disability issues in Community policies, accessibility, and employment.

Demographic forecasts for Europe suggest that the working-age population as a proportion of total population is falling. It is now more important than ever to make full use of the available working population, including disabled people. The EU Disability Action Plan emphasises the economic potential of disabled people and recognises that the contribution they can make to economic and employment growth must be further activated.¹¹

Currently, the inactivity rate of disabled people is twice that of non-disabled people, indicating both low levels of reintegration following LSHPD, and comparatively low educational and vocational training levels. Reasons for this high inactivity vary between countries, but it has been suggested that benefit traps and risks of losing benefits on starting work are major disincentives. Another possible reason may be the reluctance of employers to recruit disabled workers for fear of having to make expensive workplace adjustments.

In actions and policies designed to promote “equality of opportunities” such as the European strategy, and accessibility to goods and services and to the built environment, Assistive Technologies can indeed be of significant importance, and should be considered as major tools. In spite of the initial investment they may represent, the benefits they bring about in terms of decreasing dependency, increasing productivity and improving self-esteem are considerable.

Assistive Technology

Technology is a growing and complex field. New developments happen daily. People with disabilities can use assistive technology (AT) to gain new skills, keep old ones and live more independently. However, choosing the right technology is often a difficult task.

The evaluator should compare the unique features of a variety of devices to decide which device(s) might meet the individual’s needs. The procedures should also include assessing the environments where the person will use the device, inquiring the user’s expectations in those environments, questioning the necessary supports for device use. All of these are important steps the physiatrist should follow before prescribing an AT for his patient. But, s/he also should consider the individual preference in device use. No matter whom pays for the device, AT users are obligated to ensure the device is used. To ensure it they need to make sure it ‘fits’ them. So, they need to be informed consumers.

Rehabilitation technology and rehabilitation engineering will continue to improve diagnostic and therapeutic modalities that will be incorporated into patient care.

Information Technology

In recent years, we have witnessed the revolutionary advances of Information Technology and Telecommunications. Technological progress is now rapidly leading us to a new concept of an Information Society, where citizens with different abilities, requirements, educational and cultural backgrounds will need to perform, in the context of their everyday life activities, various interactions with multimedia applications and telematic services.

This offers new opportunities for all citizens in society, including disabled and elderly people. However, it may also introduce new barriers, human isolation and alienation, if the diverse requirements of all potential users are not taken seriously into consideration. It is important to ensure that the emerging technological developments, within the Information Society, will empower all citizens including disabled and elderly people, in their everyday life activities.

Advances in Information Technology and Telecommunications have played a catalytic role in recent developments within the field of Assistive Technology, facilitating the introduction of new products and services. Assistive Technology has applied Information Technologies to promote the socio-economic integration and independent living of disabled and elderly people, offering technological support for various areas such as interpersonal communication, housing, education, employment, recreation, among others.

This is a field that is continuing to develop and in this sense the future is unpredictable. Recognizing diverse needs and abilities stimulates creativity in the search for new solutions that will apply to all of us.

Network for Continued and Integrated Care

The demographic aging, the changes in epidemiological patterns of disease and also, in social and family structures, determine new needs in health, and consequently, new approaches to deal with these issues. Actually, specific needs of elderly and of people with severe disabilities imply an integrated process of two inseparable dimensions: health and welfare. It’s in this context that the concept and the practice of *continued care* is enclosed.

Portugal is taking the first steps in organising a network for “*continued care*”.¹² On June 6th 2006, the diploma creating the “*National Network for continued and integrated care*” was approved by the Ministries of Health and of Work and Welfare. This network is a group of sequential interventions of healthcare and/or social support, with the goal of promoting autonomy, improving functioning of the person in dependency situation, through rehabilitation, re-adaptation and social and family reintegration. This net promotes the articulation between hospitals, who deliver acute and intense healthcare, primary health care, responsible for maintaining the health of populations, patients and families and NGO’s or private organizations that provide services.

Conceptually the network for continued care seems to adequately respond to the needs of patients, families and health professionals and promises to fill some of the gaps that currently exist in the Portuguese healthcare system. The holistic perspective that the network entails is similar to the rehabilitation approach and in this sense it may also constitute an opportunity for PMR to reaffirm its values, principles and practices.

Way Forward

Sixty/Fifty years ago, when society was confronted with the need of taking care of young men injured during World War II, PMR was formally organised and went through a period of great development. At that time, rehabilitation services were designed to help a specific group of individuals, those who had a handicap, developing their potential and achieving a life as normal as possible.

The physical limitations were the main concern, and rehabilitation programs aimed at restoring the individual capacities, having normality as a pattern. Prompt by scientific and technological advances, changes have occurred in all domains of society, social, economical, political, environmental and medical.

On the edge of the 21 century, new perspectives for PMR are emerging. Rehabilitation is requested to enlarge its field of intervention. The broad scope of the specialty makes it ever more needed to complement other clinical specialties as well as to interface with the various health professionals. Population aging and the raising prevalence of chronic diseases are increasing the number of people with disabilities and dependency, thus expanding the need for rehabilitation services and requiring integrated responses for providing care.

The development of technology and rehabilitation engineering will continue to bring about new solutions for arising problems, providing new means for diagnostic and therapeutic modalities that apply to patient care; however, rehabilitation therapy must be proven and cost-effective to be acceptable to the healthcare payers.

As far as accessibility to all environments is concerned, technological developments will certainly contribute to empower people regardless their condition (disabled or elderly), in their everyday life activities. They are definitely a fundamental tool to enhance the rehabilitation field of intervention, to decrease dependency, to promote productivity of people with disabilities and to improve their self-esteem and quality of life.

A new paradigm for rehabilitation is emerging reflecting a shift in concepts. Disability is no longer viewed as merely the result of impairment. The social model of disability has increased awareness that environmental barriers to participation are major causes of disability and dependency. This approach involves not just people with disabilities and their families' but the whole society, and requires that we replace the old language of needs by the new discourse of rights.

As the UN has recognized on the International Convention on the Rights of Persons with Disability, People with disabilities are full citizens. As such, they are entitled to an array of supports and protections of the law in order to be able to exercise with all other citizens, their fundamental rights (to health, to employment, to education and so forth) and freedoms.

The shift on the perception of disability implies new approaches and new models of intervention in rehabilitation which are being shaped by the interaction of clinical, social and economical factors as we mentioned before. To enhance political investment in rehabilitation seems crucial. We need to demonstrate that it's less expensive to rehabilitate than to pay long term for dependency, considering that costs are not just economical but social and human as well.

There is still a long way to go from concepts and models to attitudes and practices towards disability. This is a demanding, challenging and long process, requiring the participation of us all. Rehabilitation professionals' along with the disability community are specially requested to play an important role on transforming social understandings of disability.

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