

Workability and disability at persons with congenital heart diseases

Assist. Prof. Dr. Corina Oancea MD PhD

**“Carol Davila” University of Medicine and
Pharmacy Bucharest**

EASOM Timisoara

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BACKGROUND

- Heart defects present at birth
- The prevalence: 7.1 / 1000 births (EUROCAT data)
- About 25% are "critical" congenital heart diseases (CHD) requiring intervention (surgery or catheterization) in the first year of life
- These types of interventions have greatly improved the survival rate, 85% reach adult age
- There are performed in the first weeks of life to optimize hemodynamics and prevent irreversible damage that occur in case of late diagnosis
- There are about 800,000 adults with CHD in the USA, 60,000 adults in Romania
- Given the low mortality rate for modern surgical procedures (under 5%) is expected in the next decade that about 1 in 150 young adults to have a type of CHD

Types of Congenital Heart Defects

- Atrial septal defect
- Ventricular septal defect
- Patent Ductus Arteriosus
- Coarctation of the aorta
- Congenital aortic stenosis
- Pulmonary valve stenosis
- Eisenmenger syndrom
- *Less often: Repaired Tetralogy of Fallot, Ebstein's anomaly, Congenitally corrected transposition of the great arteries*

Psychosocial Aspects

- Intellectual development and education
- Employment
- Life and health insurance
- Physical activity and sport
- Quality of life
- Patient organizations

Employment (1)

- Ability to obtain and maintain a job depends on:
 - Physical and intellectual abilities
 - Motivation
 - Interaction with others
 - Potential social discrimination
- Lack of employment is more common in patients with complex defects
- About 10% have total loss of work ability
- Lack of occupation has important side effects: low self-esteem, decreased social contacts

Employment (2)

- Information and counselling must take into account individual intellectual and physical abilities and to consider specific features of this pathology, eg:
 - Severe arrhythmias can disqualify people to perform certain professions: driving
 - There are some particular medical contraindications for employment in the public sector, depending on country-specific legislation: the armed forces, police

Employment (3)

- Providing adequate school orientation / training or retraining, qualification courses for learning a profession or further training, can increase the options and opportunities for employment
- A disabled person can contribute significantly and on long-term to the productivity growth and the profit of the companies
- Many NGOs have training projects for persons with disabilities and information campaigns among employers about the skills of these people and their willingness to work, job fairs for people with disabilities

Social insurance rights in Romania

- Work disability (Invalidity) pension for insured persons who have total or at least half loss of their work capacity
- Social services and benefits for disabled persons

Legislation

- Law 263/2010 on the unitary system of public pensions
- Law 448/2006 related to people with disabilities, with adjustments and supplementary regulations subsequently introduced

Work disability

- It is quantified in relation to the degree of functional impairment caused by the disease
- The degrees of work disability are specified in **Law 263/2010 - Article 69**, as follows:
 - **Work disability 1st degree** – total loss of work capacity associated to the loss of capacity to perform the everyday tasks, the person requires the assistance of a third person
 - **Work disability 2nd degree** – total loss of work capacity, while maintaining the ability to perform acts of everyday life
 - **Work disability 3rd degree** – a minimum loss of half the work capacity, the person is still capable of exerting some types of work in part time

SOCIAL INSURANCE MEDICINE

- Based on a holistic approach to the person
- Assessment (the reduction) of functional capacity
- Establishment of the degree of work disability
- Decision on the eligibility to long-term incapacity benefits
- Analysis of the possibilities of rehabilitation and social integration of persons suffering from a chronic health problem or disability

Medical assessment

- Standardized approach
- Specific investigations are needed to:
 - Define the clinical manifestations of the disease
 - Determine the disease severity
 - Assess the response to treatment
 - Monitor the progression of the disease
 - Estimate the functional impact of the disease
- Investigations:
 - Electrocardiogram
 - Cardio-pulmonary radiography
 - Cardiac ultrasound
 - Cardiac catheterization
 - Coronary angiography
- Magnetic resonance imaging

FUNCTIONAL ASSESSMENT

- Estimates the functional impact of the disease
- It takes into account:
 - (Residual) left-right shunt size
 - The presence of functional disorders (exercise tolerance, dyspnea, arrhythmias or conduction disorders, angina, hypertension, infections, etc.)
 - Pathology-specific scales, internationally validated (NYHA Functional Classification of Heart Failure, Canadian Cardiovascular Society grading of angina pectoris)
 - Data relative to maintaining / loss of work capacity and self-care

SOCIO-PROFESSIONAL EVALUATION

- It is not quantified, has a guiding role, but occurs regularly in the overall assessment of the cases
- The social insurance physician is designed to settle the cases individually
- We take into account several aspects:
 - social situation
 - financial situation of the family
 - relationships (family / community)
 - conditions and workplace relations

Criteria for granting a work disability degree

- Elaborated by the National Institute for Medical Assessment and Work Capacity Rehabilitation
- Approved by specialized commissions (cardiology) of the Ministry of Health
- They are constantly updated with the terminology and guidelines
- Approved by Government decision
- There are national criteria which ensures a transparent and uniform application

SPECIAL PROTECTION OF PERSONS WITH DISABILITIES

- Are recognized as "disabled", all persons with physical, mental or sensory impairment, who are unable to ensure themselves a normal daily activity and thus require protective measures in order to obtain rehabilitation and social integration

DISABILITY

- Evaluation of impairments in people with disabilities is carried out according to a specific scale
- Current medical and psychosocial criteria are approved by joint order of the Minister of Labour and Ministry of Health on the proposal of the National Authority for Disabled People (ANPD)
- The recognition as disabled person allows the granting of social benefits (fixed amount allowances, tax benefits, transport facilities, free medicines)
- *Non-contributory protection system, the eligibility for those benefits is **independent of the length of service***

Psychosocial rehabilitation

- Individual rehabilitation programs (social and professional skills/autonomy)
- Interventions on the environment (family/social), so to reduce disability
- Multidisciplinary teams
- Purpose:
 - Achieve a good quality of life even in the presence of residual disorders
 - Satisfying social integration

Rehabilitation of work capacity

- Initiate the rehabilitation plan to obtain socio-professional reintegration - attribution of social insurance doctor, according to the law 263/2010, art. 81(1)
- Is essential to keep informed the person concerned and to cooperate with the responsible authorities: The National House of Public Pensions (CNPP), The National Agency for Employment (ANOFM)
- To inform about The National Plan for Vocational Training in 2015: over 41,000 people receiving 2,395 free professional training programs, financed from the Unemployment Insurance Budget and European structural funds
- In this plan are also included people who have regained partially/entirely their work ability after a period of work disability
- Keep all parties informed about the Cooperation Protocol between CNPP and ANOFM to increase the employment opportunities for work disability pensioners who have regained their work ability

Socio-professional reintegration

- Is the goal of the rehabilitation plan
- Difficult to implement because of the discrepancy between theory and practice
- There are national programs but with small capacity of coverage, few results
- An option: actions carried out by NGOs (work integration programs for persons with disabilities)
- In conclusion there is a need for a standardized and scientific approach

Perspectives

- Research in the field of social security
- More emphasis on the bio-psycho-social model (WHO ICF - *International Classification of Functioning, Disability and Health* 2001)
- Better individual assessment of disability, based on ICF, with more focus on capacities
- Better approach in providing services (rehabilitation, employment, social inclusion) vs. only financial assistance



Ongoing programs of the Ministry of Labour