

INTERVENTION STRATEGIES TO IMPROVE ACTIVE AND WELL AGEING FOR DOWN SYNDROME PERSONS

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Abstract: Persons with Down syndrome (DS) face several functional problems which increase in gravity when they get older. It's very important to apply a proactive intervention that activates the ageing process, specially on the neurologic and physical decline in order to help them to have a better quality of life despite the fact that they are ageing.

The project, DS-AGEING: Development of a program to train and improve the life of Down syndrome persons, ref.: 2018-1-ES01-KA204-0507339, is focused on training caregivers and professionals from Down syndrome sector in how to deliver a proper prophylactic support and improve the life of one with DS while they age.

This article is meant to explain a functionality approach in order to address the needs of adults and older DS persons and disabilities. The knowledge about ageing must always be adapted to the particularities of this syndrome and become valid resources that can improve those individual's life.

The information will be develop in several parts that will present the problematic of DS ageing in Romania, that will be determinate by the analysis of a DS persons group from Romania and the results of implementations of the intellectual project results (E- Training Platform that could help is intended to support the whole process of "Well-Ageing").

Keywords: Down syndrome, well-ageing, active living

Intoduction

DS persons, nowadays, live almost 60 years [1]. Although this number is still below the average, some DS persons live now to their 70s and 80s [2], due to evolution of therapies and medical interventions. This trend of increase life expectancy was observed even in Romania in last decades.

Every age period of life came with different challenges and changes for the human body. Those challenges for the health modify the functionality of the individual, his family and society. And if those challenges are not well understood and cure great health problems can occur in life individual, especially in old age.

So, many things can now be told about ageing in Down syndrome because the clinicians can observe their evolution of health. Many research studies talk about the health changes that ageing can have on the body and function of Down syndrome persons that survived to ages over 60 or 70.

The longer the life expectancy, the more adults with DS will appear, with various health issues [3]. There are a lot of aging theories suggested, but neither one explain to the full the aging process [4]. Also, Esbensen underline the importance of specialized health care for this target group who have more risks for some health problems and lower for others. [3]. This specialized health care

is still at the beginning and need special effort from all type of medical and care specialities, and the results must be common and comprehensive.

Some important medical problems that DS adults may face include problems with the reproductive system, skin and skin sensitivities, hearing and vision deficiencies, diabetes, apnea, obesity, thyroid and movement deficiencies [3].

Celiac disease or gastrointestinal disorders, mental disorders like Alzheimer disease [5, 6] or depression can be frequently presented in DS persons.

Aging comes along with very many chronic diseases [7]. There is not a singular mechanism responsible for the decline encountered in elerly people, but, the decline happens during lifetime [8].

"According to the the DNA damage theory, the process of aging comes from the unrepaired DNA ". [4]

"DS adults face a premature aging " [3].

"Aging is seen as a consequence of unrepaired DNA damage accumulation. There are lower levels of DNA repair enzymes being found in DS adults" [9].

"Another theory claims that a free-radical metabolism which involves a key enzyme, CuZn superoxide dismutase, is found within the chromosome 21 [10]. The presence of this

enzyme produce the altered functionality of the tissue“ [11].

DS adults enjoy good health, but they can be suffering by chronic diseases, treatable or not [12]. Burt and all study from 1996 34 DS adults (14 females, 20 males) aged between 22 to 56. The data does not suggest that DS adults show declines in functioning [13].

Physical challenges for the persons and their family may also be better at DS and dementia, as many of these individuals can have a multitude of chronic conditions including cardiac disease, hypertension, obesity, endocrine disorders, arthritis, and gastrointestinal issues. The families know those problems and prognostic that studies underline and the future is grey for some of them because the parents also get old in the same time with their children with DS.

At the present time, DS persons may found guidelines for their health care, including guidelines specific for adulthood [14].

Doctors treating DS adults must know the special health problems of this group [15]. Prevention is the correct approach for DS persons and include general and allopathic medicine [16].

Sally Sara, in June 2008, underline so well regarding the parents of a DS adult died or get unable to provide the help that this adult with dementia might need [17]. The tutors of a DS person are feeling both happy and sad while the life expectancy increases, as they live to see the disabled person deteriorating [17].

Because of the evolution in time of medical schools and the access to medicine in the last decades, there is a huge difference of care from 30 years ago and today (for example, the Romanian case) the aging process in Down syndrome is not homogeneous and many disturbances and problems of PDS will need tools that can improve active and well ageing.

Awareness among doctors about the problems that an adult with Down syndrome can face is very important, and also early intervention is decisive [3].

The prevention can have many aspects and a therapist or trainer must have proper and concrete materials to work with in order to decide the best individualised approach for each individual with DS, because every PDS can manifest different needs and functional modifications.

However, not all responses to this target group are yet known [3]. This is a new group, which has not existed much in the past or there is no relevant data on DS children reaching adulthood [18].

There are some concerns about aging in the world population, especially in Europe, and older age is better to have a good health and low need of medical care. In order to meet those facts, World Health Organization take action since the 1990s by the term “**active ageing**”. It is about more than “healthy ageing” [19].

Active ageing can be understood different in diverse cultural contexts and in some cases it can hardly be define by some segments of the population. Some of us have the example of what we should do and how to behave in time of adulthood and seniority just by watching and memorize of our parents and grandparents actions. That mean that we are at risk to replicate the good or bad actions of our ancestors that cannot necessary lead to the same results like in their cases and we can't not get the same age and the same well-aging process like them.

In 2002 WHO release “The Active ageing: a policy framework a contribution of the WHO to the Second United Nations World Assembly on Ageing”, Madrid, Spain, April 2002 [20].

*“Health” is about “physical, mental and social well being as expressed in the WHO definition of health”. Thus, in an active ageing framework, policies and programmes that promote **mental health and social connections** are as important as those that improve **physical health status** [20].*

The word “active” is about the continuity of the social participation not only the physically activeness [20].

In 2015, the WHO refers to active ageing as “the process of optimizing opportunities for health, participation and security in order to enhance quality of life as people age” [21].

Those concepts about ageing must be adapted to the particularities of special groups of individuals that require certain knowledge from the

therapeutic point of view in order to maintain their health and well being.

Many policies developed regarding „**active ageing**” and „**well ageing**” must be adapted for the need of DS persons. The particularities of this group population must be approach by the therapists and specialists that know well what the

suitable approach is and best life style that will lead to the well-ageing that family and specialists desire.

Active ageing depends on a variety of factors and endure influences or determinants from factors that surround individuals, families and population. They include material conditions as well as social factors that affect individual types of behaviour and feelings.

By this transnational project, “*DS-AGEING: Development of a training program for improving the well-ageing of persons with Down syndrome*”, ref.: 2018-1-ES01-KA204-0507339 5 country partners, from 7 DS sector organizations try to apply a pattern of anti-ageing interventions for Down syndrome peoples that can influence the well ageing and health. The project consortium already establishes the dimensions that can be trained and can have a positive effect in the ageing process.

The project desire to promote a prophylactic modality to face and approach ageing, with all the known aspects that are not desirable for DS and that are well described by different studies and researchers.

The unitary prophylactic intervention will be the amount of knowledge form all the partners and countries. Because there are so many socio-cultural differences, the best way to make a viable and applicable training document that it fits for all is ***if the changes will be make on the behavioural determinants of ageing.***

The project consortium considers that for PDS an Active Ageing Model should take this in to account many aspects [from key action of the

project *DS-AGEING*, ref.: 2018-1-ES01-KA204-0507339 5]:

- Cognitive decline;
- Physical decline;
- Active aging;
- Interpersonal relationships;
- Independent life (without a tutor).

The approach of ageing process in DS adults must be all adapted, integrated and inclusive for the supports of DS persons, tutors and community members.

Nowadays we are facing an insufficient implementation of active ageing model to PDS that are express by lack of proper methodologies and knowledge, adapted tools, ICT support.

The process of finding a unitary approach, which can solve also the cultural, economic, social differences between different cultures and countries.

While there is a growing awareness that people with DS are entitled to medical care and services as the general population, they may be unable to access these services due to the lack of understanding about how certain conditions affect the aging person with DS and how they can be best managed [22].

Data provided by the National Authority for People with Disabilities, ***from 2018 in Romania there were*** 4537 DS persons, 1776 children and 2761 adults. 4392 with their families, while 145 people were institutionalized. The larger population is the age group 18-25 (809 persons) and 26-45 (1468 persons). The statistics included a number of 15 elderly persons with DS (plus 66 years).

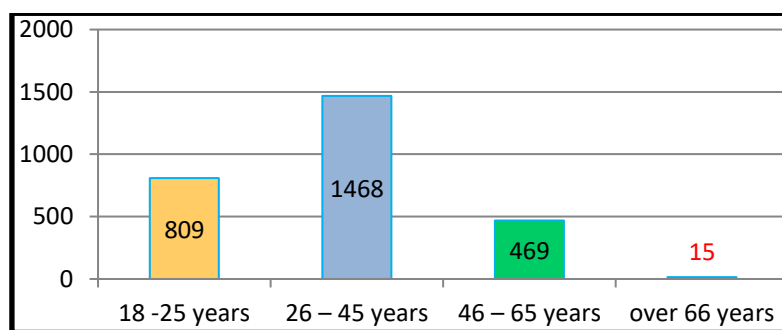


Figure 1. Romania DS Persons

Brian Skoto was positive about the issue: “the aging of the population is well know and debate in our society, the aging of the population with Down syndrome is a positive sign” [23].

Those numbers show the number of potential beneficiaries of those sorts of European projects

that try to update and develop integrated and inclusive approach and tools for specialists and tutors, like DS-Ageing.

Activities in different dimensions that will be developed in the project will be: 1) **attention** (selective, sustained, divided, alternative), 2)

communication and language (non verbal and verbal), 3) **memory** (episodic and instrumental, long term, short and.), 4) **executive functions** (planning, reasoning, flexibility, decision making, time estimation, multitasking), 5) **praxis**, 6) **gnosis** (tactile, visual, auditory), 7) **orientation** (temporal, spatial, personal), 8) **psychomotricity** (fine and gross motor skills), 9) **calculation**, 10) **facing transition events**, 11) **physical health**.

For all topics (and subtopics), 71 face-to-face activities, 33 e-training activities and 29 practical activities were created. Each training session last around 40 minutes, it is addressed to one subtopic and it include one face-to-face activity combined by other activity as a support/reinforcement (e-training or practical).

Each dimension can be trained based on a scheme that will be in presented on project web platform. The scheme will contain general and specific objectives, characteristics about the participants, the duration of the application, necessary tools and materials for the application, different

This knowledge developed by the project will rely under the available scientific technologies like ICT tools. ICT tools slowly became the new generation rehabilitation approach of disability and many studies shown that are the best complementary techniques can access many remaining resources that the disability subject have and can enhance functionality.

And by the fact that the subject can use by himself the ICT tools, at home, an e-learning or e-training platform will increase the time of activity and decrease the time and costs by the therapy with a therapist. Also, the project is focused on training caregivers and professionals of Down syndrome sector in how to deliver a proper support to persons with DS.

Multidisciplinary approaches to these issues can help the DS to live their life to the full, by maintaining the optimal functional capacities and ease the burden of complex and multiple diseases. Policies must respect cultural contexts and influences and understand ethical problems.

After Head E. et al. [24] the modification of the lifestyle and monitoring their health can make a DS person age well.

The plus of such project, like DS Ageing, is the involvement of ICT tools and the decrease human resources involved in the therapy and in supporting the functionality of PDS. The e-training platform is a good instrument that help the users to do at home different exercises, this way the training is applied more often, at home,

even if the specialist is not present, and the results can be more rewarded on long term.

Conclusions

The DS life expectancy continues to improve.

The transnational project tries to plan the future of adults with DS. Thinking in advance, creating a sustainable plan, both for the DS person and his family, requires promoting prophylaxis like a life style since at the young adult with DS.

The project does not try to study the ageing process, the outcome of the project are meant to be supporting for the fight lead by the person, family, therapist form all the domains of Down syndrome to relent and decrees the health and functional problems related to old age.

Improving the skills and knowledge of all the persons from the DS field about how to understand the Well-Ageing can be the best modality to have materials to support the DS persons needs their families and the specialists.

This intervention strategy approach develop by DS-AGEING project is meant to be an active and proactive intervention on behaviour, also on long term, like all prophylactic therapies should be. The Down syndrome persons should be taught by a trainer to adopt a life style that can slow the speed of ageing and train the mind and body functionality.

Authors' contributions. Each author contributed equally to the study and writing of the article.

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