



## Cerebral palsy and ageing: A society for all ages

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### Abstract

Some of the reasons why we need to know the needs of people affected with cerebral palsy in their ageing process are, first, the socio-demographic reality in this group of people with cerebral palsy that reaches the stage of aging, with an increasing life expectancy, is becoming more numerous and more demands are posed. Secondly the finding supported by both the professionals and the scientific community shows there are different elements in their ageing process compared with the ageing of the general population. And, thirdly, the important and frequent demanded by families, professionals and associates answers and solutions to the new needs that these ageing processes pose. The concept of cerebral palsy has evolved towards a biopsychosocial model and this significant change should include the impact of the ageing process. This approach attempts to provide comprehensive care and promote wellness, quality of life and personal autonomy for the elderly with cerebral palsy.

**Keywords:** disability, perceived needs, assessment, intervention, quality of life.

## Introduction

Cerebral Palsy (CP) is nowadays the most frequent motive for physical disability which prevalence is 2-2,5 per 1000 births (Camacho, Pallás, de la Cruz, Simón & Mateos, 2007). Life expectancy in this people is increasing due to the improvements in prevention, attention and rehabilitation that constitute one of the mayor indicators of wellness and makes it to be shown as a new challenge for families and professionals, and of course for people affected with CP on their own (Robaina-Castellanos, Riesgo-Rodríguez & Robaina-Castellanos, 2007).

There is almost no evidence about the changes that take place during people's with this disability ageing process. Time passing trade combined to CP characteristics does not allow representative aspects of adult and older people with CP to be properly represented. The fact that is already known is life expectancy is now longer than in past decades (Brooks, Strauss, Shavelle, Tran, Rosenbloom & Wu, 2014)

Old people with CP's sociodemographic profile's study helps in the understanding of their ageing process, a barely studied reality up to these days, but that has got an important relevance. People with CP, both congenital, acquired in the birth or during the first terms of life, has shown along centuries a lower life expectancy related general population (Blair, Watson, Badawi & Stanley, 2001)

and they hardly survived more than thirty or forty years of age (Strauss, Rosenbloom, Shavelle & Brooks, 2012). Predictions resulting from life expectancy studies show a minimum difference with general population excepting epilepsy and severe motor dysfunction cases (Hutton & Pharoah, 2006)

The knowledge of mortality causes and risk factors involved in ageing process in CP will allow accurate prevention strategies to be set up, to propose an appropriate treatment, establish an early diagnostic and try to avoid any emerging illness.

General population's longevity will have an impact in illness in the following years, related expenses and attention services demands will undoubtedly increase. Support and care services will be necessary proportionally to life expectancy's increase (Abellán, Vilches & Pujol, 2014). Knowing this facts and transferring them to the collective allowed, it must be anticipated the high number of people affected with CP that will be demanding services and will need support in reaching their old years.

When discussing about CP not only people affected with the illness must be considered, their families are also a very important factor that provides them with maintenance and support along all their life. Nowadays it is probable the person with CP over living his own principal caregiver (CERMI, 2012), this is why families also need

accurate interventions, as Berzosa, (2013), Madrigal, (2007), and Verdugo, Rodríguez & Sánchez, (2009) propose. These authors, relating to the ageing in the members of people with disability family, after having studied the own families demands, consider that interventions must be consistent with their needs.

Disabled people's ageing process is as variable as in the rest of the population (Evenhuis, Henderson, Beange, Lennox & Chicoine, 2001; Thorpe, Davidson & Janicki, 2000). Some researches evidence important physical complications, walking limitations and participation restriction (Margre, Reis & Morais, 2009). Individual differences have a core importance in this process, and these differences are intensified while socio-political, cultural or sanitary factors go on appearing, because all of them take part in ageing process (Colver, Fairhurst & Pharoah, 2014). Therefore, examining and considering common and individual factors of ageing in disabled people will allow the adjustment of given support, and the possibility to readjust this support to disabled old people's preferences; such as helping them in solving problems and covering needs. The purpose is that these services and support are adapted to the individual needs because of their heterogeneity.

This paper goal is to collect all the relevant information related to changes that take place during the ageing process in people

with CP in order to raise new intervention and research lines and be able to serve the needs these changes generate.

### **Methods**

A generic bibliographic search was made among the following databases: Medline, Scopus, ERIC and ISOC; using cerebral palsy, aging, ageing, elderly and adult as descriptors.

In a former search 211 publications referred to ageing process in people with CP, 75 out of then were selected as bibliographic relevant references to this paper. These publications are brought together into: journal articles, reviews and studies. Most of the texts appear in neurology, ageing, disability, rehabilitation and evolutive journals.

So far, most studies are referred to descriptions and studies related to biological changes and their effects in CP. As the limitations of mainly descriptive and correlational studies have been revealed, the need to make further multivariate analysis and to standardize assessment procedure in CP and its implication in ageing process demands using methodological procedures with the highest severity.

### **Cerebral palsy**

CP has been defined and classified in different ways (Robaina-Castellanos et al., 2007), fact that has constituted a limitation in epidemiologic results interpretation, because

they need not only reliable instruments to establish measurements and comparisons (Pueyo & Vendrell, 2002) but also to depart from common concepts and criteria (Camacho et al., 2007) in order to determine CP's prevalence.

International classification of functioning, disability and health (ICF, 2001) offers a conceptual biopsychosocial reference frame about disability and provides a multidimensional approach that joins personal intrinsic attributes (physical, cognitive, behavioral) and extrinsic, as environmental factors that can hinder or facilitate development levels and disability.

Nowadays, attention is centered in the intensification of function through all human functioning domains, through task adaptation or environmental modification, because it is recognized that a person with CP can reach functional independence and promote a good life quality even in the presence of some limitations. In relation with this, Rosenbaum, Paneth, Levinton, Goldstein, & Bax (2007, p. 9) show a definition that describes CP as: A group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behavior; by epilepsy, and by secondary

musculoskeletal problems.

This definition brings in a common language that enables communication improvement between different professionals, helps in the identification of each affected person's functional status and in the identification of their needs profile.

### **Cerebral palsy and ageing: a double experience.**

World Health Organization (WHO, 2011) estimates disability's prevalence in 15% approximately. Reality is that exact percentage among total world population is unknown. The rates handled are approximate estimations, based in measurement instruments based themselves on questionnaires fulfilled in several countries.

European report elaborated by the People with Disability and Old People's Ageing Experts Committee reveals a raise both in quantity and seriousness of impairment in the elders, that have made policies about impairment in Europe to begin their journey. Each time there is more people that reaches their old years and medicine allows those who have any chronic disability to live more than before, therefore total quantity of people with disability in society has increased considerably. In their ageing, these people often suffer the double disadvantage of ageing and also having an impairment, circumstance that exacerbates this troublesome because only in few occasions people with disability are

prioritized when providing services to old people (Cayo, 2014) and because information about their needs is scarce.

Ageing process in disabled people refers to a process that takes place in individuals with an early impairment, these people have got resources in order to face this adverse circumstances that go on appearing along their lifetime and make them able to strengthen their tackling ability, adapting themselves after that in a more proper way to ageing process (CERMI, 2012), a higher grade of disability can generate a higher grade of overcoming (Arellano & Peralta, 2013; Wehmeyer & Abery, 2013). Even so, these strategies in old people require changes in rhythm and environment. People that live together with disability along their life, are often faced to adverse situations and, therefore, have the opportunity to acquire the ability to adapting successfully to problems (Horsman, Suto, Dugeon, & Harris, 2010), assimilation of new trouble is easier, due to the learning processes, adaptations and repertoires associated to disability than have been made along their living, and, in the ageing process case, changes are progressive. Although getting older is for everyone a complex, dynamic and continuous process, it is distinct by the biography, attitudes, and skills each person can manage to face it (Ministerio de Sanidad, Política Social e Igualdad, 2011), it is true that there are differences between ageing process of people with disability and the

general population, clinical involvements and a higher mortality, principally (Turk, 2009).

Aguado & Alcedo (2006) contributions show growing older and keeping a certain wellness feeling is a hard task for the individual and for society. It is known population that grows older is not an homogeneous group and that there are differences that must be identified and known in order to provide an adequate answer to problems (Aguado, Alcedo & Fontanil, 2012). Although there are some common aspects in people`s ageing process, there are also some differences when people get older with a disability. That is the reason why it is convenient to difference between ageing process in people with disability and people that acquire a disability as a consequence of the ageing process itself. Or what is similar, to distinguish between old disabled people and old people with disability (Ministerio de Sanidad y Política Social, 2011)

Ageing is accepted as a natural process translated in wide and diverse changes and it is plausible to think it can have a higher repercussion in disabled people`s life, but, we must admit we leave from a huge ignorance about what is ageing with a long term disability. Support needs must be considered and their intensity can vary depending on different disabilities and people that suffer them. Following Ramos (2002), changes that appear are connected to physical, emotional and social factors, a stimulant and enriched

environment can help to delay or prevent from apathy development, immobility, isolation and retract, on the contrary, promote deterioration and reduce interest. Therefore, ageing process can't be understood as a unitary process, we can neither consider a specific way to grow older for each collective or kind of disability. Ageing process is as variable as in the rest of the population and individual differences are a keystone in this process.

Disabled people are exposed, at least, to the same kind of medical trouble than the rest of the population. Most of the disorders that can be found more frequently in population with disability, such as for example motor function, sensory, endocrine, cardiovascular, respiratory and osteoarticular problems, that are not different from general old people, but they are more noticeable in this population (Haak, Lenski, Hidecker, Li & Paneth, 2009; Margre, Reis & Morais, 2010; Morgan & McGinley, 2014; Navas, Uhlmann & Berásategui, 2014). If we add psychological to this physical changes in this people's life stage it can be understood that this disorders are potentially problematic, not only because the discomfort that they create but also because of the adaptations they need in their personal daily living and the additional support devices that are needed to compensate altered or decreased functioning (Trieschman, 1995). Now then, these changes do not appear invariably, neither affects every person in the same way. Biological and social ageing can be

correlative or not. Ageing effects will vary based on the state of health, specific dysfunctions and support availability and covered needs. It must not be forgotten also that attention quality and social support are determinant contextual factors in this ageing process.

### **Comprehensive Care**

The objective is to achieve the comprehensive care from the specificity of this type of disability by the global nature of the disorder, the diversity aspects manifested: motor, communication, cognition, sensory, affective social, health, welfare etc. and the variety of consequences in each person. The attention to the people with CP is a process of construction. Person affected, family and professionals must have a positive attitude positive to contribute to achieve the maximum development and improve their individual performance (Royal Legislative Decree 1/2013).

Considering the particularities of the elderly with CP, after an assessment by an interdisciplinary team, and taking into account the information provided by the person and the family, personal intervention program has to be designed. Trying to apply a comprehensive model to give them care and the promotion of their welfare, quality of life, personal autonomy and full development including prevention, attention to diversity and responding to the specific needs that will

benefit all citizens (Leturia, Díaz, Sannino, & Martínez, 2014; Verdugo & Schalock, 2013).

As regards intervention it must be bear in mind a heterogeneity of proposals according to the abilities and functional limitations with respect to motor, sensory, intellectual aspects, attention, epilepsy, musculoskeletal and other significant issues or problematic in this stage of the life of people with their needs.

Aging throughout the life cycle is an adapted process, which the individual manages biological-psycho-socio-cultural conditions through.

The goal of aging is to get each person to develop their potential for physical, social and mental well being throughout his life and to participate in society according to their needs, wishes and capabilities. Some aspects in the care of everyday life such as autonomy, independence and quality of life they can help to achieve this goal and make a positive experience of aging.

### **Conclusions**

Life expectancy has increased in people with CP, since they certainly live more than in previous decades. Also it was found that there is a wide variety of origins, causes consequences and support needs.

It is also representative that few data on the determinants in the aging process are known. New challenges are been created. There are few studies about effects in mobility, communication, physical and emotional

changes in aging. People with CP have a higher risk to acquire new difficulties and disability conditions along their life. Risk factors are many and varied, genetic and styles of life and social relations were may explain the difficulties and limitations added to disability. The physical and psychological changes that people with CP live in this stage of life are quite unknown and added to the already existing.

There is evidence of the importance the ageing of persons with disabilities has through an integrated approach. There are necessary studies that meet the specific needs that are people with disabilities, the families, and the systems of care being carried out. The old age of people with disabilities is characterized by a decline in the perception of quality of life due to the loss of autonomy to carry out activities of daily living.

Older people with CP contribution to the population's ageing process must be recognized. These people carry most of their life adapting the situations generated by disability and enhancing their resources and experiences and could be considered as contributions to the well being of society in general.

Empirical support is needed for a thorough approach to the needs of this group, because the lack of these studies is an important obstacle to comprehensive care for these people. The main challenge and opportunity will be to investigate the perceived

needs of people with CP to be able to raise realistic actions and effective programs. It is important to study the specific needs of this group.

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