

Mini Review

Family Caregivers of Patients with Neurodegenerative Diseases: Life Challenge

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Abstract

Aging is a continuous process from birth to death, which encompasses physical, social, psychological and spiritual changes. Therefore aging reflects all the changes that occur over the course of life. Often aging can be complicated when it is associated with neurodegenerative diseases, one of the plagues of our century. In this mini review we make an in-depth assessment of the impact of the disease on the everyday life of patients and caregivers, including the psychological and social barriers they have to face, and the economic burden on both family and society.

Keywords: Caregivers; Aging; Neurodegenerative diseases

Introduction

Population aging is prevalent worldwide, and the number of older adults is increasing at an accelerating rate. It is estimated that by 2050, in many nations at least 20% of the national population will be aged ≥ 60 years [1]. Of note, the most substantial increase has been observed in the most elderly group (aged > 85 y). Population aging occurs at various rates in different geographic regions. Although at present Europe contains the most aged population, it is anticipated that by 2050, Asia, South America, and Africa will experience the most rapid rates of increase of population aging. These demographic changes are exerting substantial and growing pressure on health care in many countries worldwide [2].

We hope we will be vigorous right up until the very end, and we are constantly seeking an 'anti-aging elixir', e.g. immortality pills, or creams that will help to revive our youthful vigour and appearance, but aging still goes on relentlessly, day after day, and affects the cells of each organ in the body. Aging is a continuous process from birth to death, which encompasses physical, social, psychological and spiritual changes. It is characterized by a progressive deterioration of bodily functions with increasing risk of failure over time [3]. Therefore aging reflects all the changes that occur over the course of life.

This time-dependent phenomenon results from the accumulation of damage during life, and many studies have improved our understanding of the possible causes of this damage, and the underlying molecular mechanisms. Today it is well known that the entire process is hierarchically organized, beginning from intracellular events and followed by changes at cellular, systemic, and ultimately organism levels. The intracellular and cellular events that contribute to aging include genomic instability, telomere attrition, epigenetic alterations, loss of proteostasis, deregulated nutrient sensing, mitochondrial dysfunction, cellular senescence, stem cell exhaustion, and altered intercellular communication [4]. The consequent damage can alter cell populations or function, thereby leading to a dysfunction of physiological systems.

Aging can be complicated when it is associated with neurodegenerative diseases, one of the plagues of our century.

Since, the increase of the elderly population is a virtually worldwide phenomenon, the incidence of age-related neurological pathologies such as Parkinson's disease (PD) and Alzheimer's disease (AD) is posing a growing, significant medical and economic problem [5, 6]. Aging manifestations are described and listed in Table 1.

Role of the Inflammation in Neurodegeneration

Neurodegeneration is a highly complex molecular process causing a loss of neurons, often accompanied by neuroinflammation. Neuroinflammation is defined as the brain's activation of the innate immune system, and its main function is to protect the central nervous system (CNS) against infectious insults, injury or disease [7]. Thus, neuroinflammation can have both positive and negative effects in our brain: positive when the inflammatory activity lasts a short period of time because it is considered neuroprotective in order to remove insults, negative when the neuroinflammation is chronic associated with harmful consequences for the CNS. Microglia cells (specialized macrophages in the brain), when activated, release large amounts of pro-inflammatory factors, including cytokines such as Interferon- γ (IFN- γ), Tumour Necrosis Factor (TNF)- α , and various Interleukins (IL), like IL-1, IL-6, IL-8, IL-12, and IL-23 [8]. These factors are crucial components of the inflammatory response in the brain under pathological and chronic neurodegenerative conditions. Moreover, microglia neuroinflammation is also commonly associated with the production of reactive oxygen species (ROS) and NO-derived reactive nitrogen species (RNS) [9].

In this report we make an in-depth assessment of the impact of the neurodegenerative disease on the everyday life of patients and caregivers, including the psychological and social barriers they have to face, and the economic burden on both family and society. Some information about the help that can come from the WEB in the Internet era is also provided.

PD and Caregivers: Quality of Life

PD, characterized by the degeneration and progressive loss of dopaminergic neurons in the midbrain substantia nigra pars

Table 1: Aging manifestations.

BIOLOGICAL ASPECTS	PSYCHOLOGICAL ASPECTS	SOCIETY ASPECTS
muscles lose mass and tone	short term memory seems to decrease	family relationships are vital
The skeleton loses its resiliency	reminiscence: often we live in our past	sometimes individuals appear to act like children
skin loses its elasticity and natural oil, becomes thinner, and some people develop 'aging spots', dark areas of pigmentation	Depression	caring and nursing of the elderly
decreased sensitivity of taste and smell		
Sight and hearing disorders		
Systems disorders (circulatory, digestive urinary and reproductive system)		

compacta (SNpc), leading to a reduction of dopamine in the striatum, is the world's second most common neurodegenerative disease [10]. PD affects 1%-2% of the population over 65 years of age [11], and is associated with motor dysfunction. Traditionally, the typical motor-related manifestations of Parkinson's disease are bradykinesia, rigidity and resting tremor, which results from progressive loss of dopaminergic neurons in the SNpc. Patients can also exhibit a number of non motor manifestations before the onset of motor-related manifestations, such as anxiety, depression, sleep disorders and gastrointestinal disorders [12, 13]. In humans, normal aging requires care and attention by relatives. In PD patients the aging process is strongly exacerbated since the quality of life (QoL) of the patient as well as the family is compromised. The World Health Organization (WHO) defines QoL as "individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns." According to WHO, health-related QoL (HRQoL) is a broad-ranging concept affected in a complex way by a person's physical health, psychological state, level of independence, social relationships, personal beliefs, and their relationship with salient features of their environment [14].

PD patients have a low QoL, due to the motor symptoms of the disease, and need someone to help them with daily activities. In fact, PD does not only affect individuals but also their family members on a daily basis, often resulting in heavy changes in their lifestyle patterns [15]. It is recognized that caregivers of people with PD also have a reduced QoL [16], with reduced social activities and work schedules because of the need to be more involved in caring. Caregiver spouses are less likely to spend time outside the house or to take a holiday than non-caregiver spouses, and older spousal caregivers often have to face age-related challenges themselves [17]. Moreover, the research by Eloise H. Tew et al, confirmed that depression and anxiety represent the largest negative predictors of QoL in caregivers and additionally highlighted the role of personality factors. In this regard, neuroticism seems to be negatively associated with psychological QoL amongst caregivers, whereas conscientiousness, openness and extroversion appear to be positively associated, playing protective action. These observations suggest that caregivers who show a high level of neuroticism need increased levels of psychological support [18]. O'Reilly et al. reported that caregivers of patients with PD had more episodes of chronic illness and a greater use of tranquilizers, a five-fold increase in psychiatric morbidity, and a restricted social life as compared to controls [17]. In addition, mental health symptoms are the symptoms of PD associated with the greatest impact on caregivers' distress [19].

Caregiver Experiences

In families with a demented patient, caregivers are dominated by fatigue and pain, but are not necessarily fragile. Recent studies indicate that the dynamic equilibrium is robust and infringed only when dealing with serious events, such as illness or death of one of the care providers (resulting in a sudden overload for the other family members), or following a further aggravation of the patient's condition [14]. A further cause for disruption of care consists of behavioural disorders, especially insomnia and nocturnal wandering. The information provided by the doctor about the disease is considered a very important element of support for the family.

The possibility of proper family care is based, as regards health personnel, on two fundamental aspects: information and support. The family should be fully informed about the nature of the disease, the patient's true capacities, the need to involve them in all activities of daily living, and possible changes to the home environment that could facilitate adjustment processes [16].

Particular attention should be paid to explaining the steps to be taken when faced with numerous symptoms that characterize the course of the disease, and so are not always predictable. The doctor's instructions are particularly important for disorders such as the progressive cognitive impairment or ceaseless walking up and down, for little or nothing can be done to control these pharmacologically [18].

A particularly delicate moment is the first meetings with the patient and family members: the doctor must be aware that the behaviour, described as "strange", for which "a bit 'of the time he is no longer himself," is due to the disease; that certain reactions are not easily controlled; it is also important to be prepared for the variability of the disease, that requires continuous adjustments [16].

Family members also report more or less manifest feelings of sadness, discouragement, loneliness or tiredness; guilt is frequent, linked to the refusal to admit the problem, or shame for the family, to the fact that sometimes they lose patience or think it would be better to fall back on a nursing home. It is necessary to examine these feelings, evaluating them objectively and discussing them, as far as possible, with other family members with similar problems [17].

PD caring is very difficult, and consequently much research has been focused on the stressful aspect of the caregiver role, while only a limited number of studies have started to explore the rewarding aspects as well. In research by Habermann et al. [20] the positive experience that adult children had with PD patients is stressed, in particular a son who moved into his father's house and cared for his

father with PD five days a week said: -He came up to me in the kitchen one day and said: “uh can you button my shirt for me? My hands are shaking today”. And I said: “okay” and I buttoned it and...he stood there for a minute, and he started to say something and ...he just kept standing there and he tried to say something again and...finally he said: “Thank you”. And I told him he was welcome. And we went on about what we were doing- [20].

In this study it also emerged that if caregivers are positive the PD patient is also more positive and his daily activities are improved.

However, PD patients do not just need help with buttoning a shirt, walking, eating, but they need motor and stretching therapy, breathing, facial- mimicry and phono-articulatory exercises, group activities, and exercises to improve bowel transit, as well as logopedic therapy to improve speech [21, 22].

Obviously, relatives can choose to take PD patients to nursing homes where specialized staff can help the patients, but the lack of family environment could have negative effects on PD patients.

Telemedicine Applications

Nowadays, we live in a technological world, and technology, an integral part of life, helps us in various ways. For PD disease, for example, since the disease is related with age, and the global population is aging more and more, the number of individuals with PD will increase, so developments in devices and health care where care is very limited or absent will ensue, and an increasing focus on telemedicine and tele-health support caregivers.

Telemedicine or “healing at a distance” [23] involves remote delivery of health care services using telecommunications technology (videoconferencing, e-mail, and other forms of technology). Thus it is a technique, or process for service delivery, which makes use of various technologies to exchange information. Its primary purpose is to increase access to care. A major benefit offered by telemedicine is the avoidance of travel, by patients, their carers and health care professionals. Use of telemedicine can reduce the cost and the time of any travel required, and leads to faster delivery of medical services. Avoided travel is also an environmental benefit of telemedicine, and one that is becoming increasingly important [24]. In wealthy nations such as the United States, over 40% of individuals over 65 years old who have been diagnosed with PD have never met a neurologist, and they are approximately 20% more likely to fracture their hip, be placed in a skilled nursing facility, and ultimately destined to die [25]. In less wealthy nations, such as Bolivia, door-to-door prevalence studies have found that none of the individuals identified with PD have sought, much less received, care for their condition [26]. With technology, more individuals can directly connect to care service or indirectly to the expertise that they need. The global market for telemedicine services is growing rapidly, powered by falling telecommunications costs [26, 27]. Internet-enabled communications, especially interactive audio and video conferencing, can increase access to that expertise. Some of the most mature telemedicine programs are found in Canada, the Netherlands, and parts of the United States [28]. Wherever access to neurologic expertise is limited, either by inadequate numbers of providers or impaired mobility of patients, exists a potential opportunity for introducing telemedicine to facilitate that access [29].

Neurology telemedicine, also known as ‘teleneurology’ is a valid device to help PD patients and their family. In fact, studies have shown that telemedicine is useful for the evaluation and management of PD, where patient travel may be especially challenging and costly [30]. Today everybody has a Smartphone, which allows us to be connected with the world, and is also a way to access medical expertise. Caregivers, using telemedicine, feel less burdened, for different reasons: they can consult experts from any part of the world, and connect to care. Moreover, telemedicine visits are reimbursed at the same rate as face-to-face care, as well as receiving a telemedicine premium to encourage use. Caregivers can improve their QoL, in Tele-support groups [31]. The benefit of caregiver support groups has been seen in other chronic diseases such as frontotemporal dementia, cancer patients, and in the chronically ill elderly [32].

One study showed that caregivers of patients with dementia were comfortable using telecommunications technology, making this a feasible intervention [33]. These caregivers found it helpful to communicate with other caregivers, participate in group discussions, and learn about resources [34, 35].

One drawback of telemedicine is the potential to disrupt the traditional doctor-patient relationship and the resulting reluctance to implement the technology process, with human contact, personal interaction, and direct communication valued as critical components of effective and compassionate care [29].

Conclusions

From what has been illustrated above, it is essential to realize that during the course of the disease, there are points of reference to which the family can always turn as they face new problems. Some hospitals have group meetings with family members of patients, to provide psychological support to their relationship difficulties with the demented. This may include education programs aimed at families to improve the quality of life delay institutionalization of dementia patients. Relatives who meet periodically, under the guidance of a health professional, have a better knowledge of the disease, a lower sense of isolation, overcoming some feelings induced by the illness of a spouse, as well as a greater awareness of their aims, and greater ability to deal with common everyday problems.

Often, we think that people with PD are a burden in our life, because they introduce daily limits and prevent us from organizing holidays or future events, but we must remember that Parkinson patients suffer greatly, as they see their body change and abilities decline. They suffer shame and embarrassment and know they are a problem for their family.

It is very important to focus on the person with PD and make them feel wanted and important. Meanwhile, we must hope that in future society and scientists will provide ever more efficacious ways of helping and supporting caregivers and relatives.

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