

## The retirement impact in people with Parkinson disease during active age

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### ABSTRACT

Our objective was to comprehend the retirement impact in individuals with Parkinson disease during active age. We conducted a qualitative study using as Methodological Reference the Theory Grounded on Data. We interviewed 30 people with Parkinson disease, from those six were retired during active age. The data collection was in September 2013 to April 2014 and analyzed through open coding, axial and selective techniques. From the analysis, four categories emerged: retirement and identity in Parkinson disease; the incompatibility between the desire and the capacity to work; disconnecting and facing reality; the unexpected from retirement. The results indicated that people face difficulties in the disability retirement process, and we identified the need for emotional accompaniment and preparation for this transition moment in a way to stimulate a productive living, even with Parkinson disease.

**Descriptors:** Parkinson Disease; Retirement; Chronic Disease; Geriatric Nursing.

### INTRODUCTION

Parkinson disease (PD) is considered a degenerative condition of the central nervous system that affects mainly the motor system, characterized by classic motor signs of the parkinsonism associated with Lowy bodies and loss of dopaminergic neurons in the black substance<sup>(1)</sup>. Regarding the epidemiology, PD represents 80% of

parkinsonism cases, majorly incident in people older than 50 years and prevalent in about 550 per 100.000 people when 70 years old<sup>(2)</sup>, many still during reproductive age and with professional and family responsibilities.

People with PD can have their quality of life affected because they live with conditions related to physical limitations, with significant changes in their routine, compromise in the functional, professional and social capacity<sup>(3)</sup>. These changes can directly interfere with the labor activity, affecting their ability to perform tasks, and it can even cause depression, isolation and withdraw from the job market.

The economic consequences for people with PD include lower employment and income rates, impacting social life. In Sweden, among people with 10 or more years of disease evolution, 24% stay employed and 6% work full-time<sup>(4)</sup>. In Ireland, about 88% of people with Parkinson remain in work after the first diagnostic year, 40% after five years and 14% after ten years<sup>(5)</sup>. In Brazil, there are no statistical data about the employment rate of people with PD.

In a study about the context of Brazilian Public Health Policies for patients with PD, the retirement through the Social Welfare is noticed as a benefit to Parkinson patients that can contribute to the improvement of their condition and quality of life<sup>(6)</sup>.

Disability retirement is the benefit given to the person who, “using or not the disease support, is considered incapable of working and not susceptible for rehabilitation to perform an activity that will guarantee subsistence”. According to data from the Social Welfare, between 2013 and 2013, there were 468.378 disability retirement payments given in urban areas. From this total, 100.902 (21.54%) in the South Region, of those 31.903 in Santa Catarina<sup>(7)</sup>. In this context, the relationship of PD with work involves multiple questions related to loss of social and power roles. Probably, the work leave due to retirement, when programmed as well as when resulted from early disability – is the most important loss in the social lives of these individuals<sup>(8)</sup>.

Thus, the study aimed to comprehend the retirement impact in people with Parkinson disease during active age.

## METHODS

This is a qualitative study with the Theory Grounded on Data (TGD) as Methodological Reference. This theory aims at the perception knowledge, the meaning or the way how people define events or reality and how they act with their beliefs<sup>(9)</sup>.

The study is part of a macro project entitled “Living with Parkinson disease”, where 30 people diagnosed with the disease participated and they were registered in the Parkinson Association of Santa Catarina (APASC). The inclusion criteria were: diagnosis of PD; preserved cognitive condition, according to the Mini-Mental State Examination (MMSE); and conditions to verbally communicate with the researcher.

People registered at APASC were invited to participate in the study by telephone or in person. The data collected from recently diagnosed people showed that to live with PD can be permeated by many symbols during the process of living with a chronic disease. Thus, to find data to corroborate and/or direct such finding, we composed the sampling groups: sample group 1- People with up to five years since diagnosis (incomplete): 14 participants; sample group 2 – people with five to 10 years since diagnosis (incomplete):

seven participants; sample group 3 – people with more than ten years since diagnosis: nine participants.

From the participants, six reported retirement during active age, due to conditions imposed by the disease. The six interviewed were part of this analysis *corpus*, being three women and three men aged 44 to 60 years during the data collection, and Parkinson disease diagnosis varying from two to 10 years.

We collected the data between September of 2013 and April of 2014 through in deep interviews, with questions formulated in a broad and general way, to contemplate a variety of experiences and also restricted, to extract and reveal the particular experience of each participant<sup>(9)</sup>. For that, we used guiding questions, as: - Tell me about your experience with Parkinson – After the disease diagnosis, was there any modification in your daily activities?

Other questions emerged from the established dialogue based on initial questions and to deepen the findings in previous interviews.

We entirely recorded and transcribed the interviews, and we analyzed texts according to coding techniques of the TGD, processed in three steps: open coding, axial coding, and selective coding. In this methodology, data collection and analysis are conducted in an alternated sequence: the analysis starts with the first interview that will lead the next. That is, the analysis leads data collection<sup>(9)</sup>.

The study was submitted to the Ethics in Research with Human Beings Committee from Universidade Federal de Santa Catarina, which approved it under protocol nº 329.662. The participants read, understood and signed the Free and Informed Consent Term. To keep their identification, study participants were nominated with the letter “P” from participant, followed by the Arabic digit in the chronological order of interviews: P1, P2, P3 and so on.

## RESULTS

The TGD analysis process allowed unveiling the central phenomenon “Living with Parkinson disease”, from which four related categories emerged from the retirement impact to people during active age: retirement and identity in Parkinson disease; the incompatibility between the desire and the capacity to work; disconnecting and facing reality; the unexpected from retirement.

### Retirement and identity in Parkinson disease

Study participants had to stop working due to limitations imposed by PD, which caused many feelings, as frustration and sadness, evident in the following speeches.

*[...] I kept working, but Parkinson, in some cases, leads to depression; then I got into a depression phase, I've started to have crying crises at work (P1)*

*[...] at age, more or less half age, still young, being 40 years, you are not prepared to retire with a neurodegenerative disease, so this was bad for me [...] (P2)*

### The incompatibility between the desire and the capacity to work

In the participants' speeches, we noted physical changes imposed by the disease and its relationship

with work.

*[...] I can't work, I can't do anything, because you work one day, stay ill for a week, I have too much muscle pain (P3) I retired due to Parkinson; the doctor said: "I'm going to refer you because you have a right, everybody has". Then they gave me the benefit. I had many difficulties to do things. The person with this disease is different (P6)*

### Disconnecting and facing reality

It is noteworthy that in its majority, people retired by disability does not go through professional guidance to end their relationship with work, there is no planning neither preparation for this process, as perceived in the following speeches.

*[...] I wasn't producing anymore, it started to turn into difficulties at work, then I took a medical leave, and now I'm retired due to disability (P1)*

*[...] I'm retired nowadays, I retired due to disability [...] they proposed a medical leave period to me that I've accepted. Then after, this leave was transformed in retirement without consulting me, then my professional project went all under water; I felt really down with that last semester, I think I was really depressed [...] (P5)*

We still note in the speeches the relationship of the individual with work.

*[retirement] this part is cruel, I was 41 years when I received the diagnosis, and at 43 years I retired. There was no preparation; in fact, you know that is going to happen, earlier or later it is going to happen; to me it was a strong impact [...] (P4)*

*[...] It was a disaster to me in this aspect, because I gambled all my cards in a doctoral program, I didn't have a consolidated carrier, but I gambled that at the end of the doctoral program I would be taking exams to consolidate this carrier. What happened? I received the diagnosis, and it felt like a bomb because in one semester I had a strong physical decline, I had a large workload. Then, at the end of the semester, they sent me away [...] (P5).*

### The unexpected from retirement

Many people have their work trajectory interrupted by a disabling condition, a situation that can be observed in this speech.

*[...] the hardest was the retirement; [...] when you are at a senior age, you are retired, you stopped the active age and then the diseases come, you are not prepared for that (P2)*

Participants referred to have no time to be prepared:

*[...] I didn't have any preparation, it was my preparation. Thus, at the time when I was away I prepared myself, I won't be able to have the same rhythm", [...], and I wasn't the same anymore, I couldn't execute the same tasks, with the same speed, with the same energy, it was another rhythm (P2)*

*[...] after I found out that, for this part of labor medicine, they don't have this understanding, because they are hiring someone that they don't know how much time of productive life it will be, so to me, it was a shock, it turned my life upside down (P5)*

## DISCUSSION

In the capitalist society, the human being is evaluated by what is produced, and personal and family

income comes through work. Within labor activities, only those conducted outside of the domestic context are the ones valued and recognized in this cultural context, strongly influencing the personal history of individuals<sup>(10)</sup>.

Under the psychology sight, work is a self-esteem affirmation and valuing of the human being when facing the surrounding society, and for this reason, the retirement can affect physical and psychological well-being<sup>(11)</sup>. Work identifies a person in regards to capacities and the feeling of belonging to a group and, the value that it represents to the person and, to others.

When compared to the general population, individuals with PD become unavailable for the workforce earlier than those without the disease<sup>(12)</sup>, as observed in the speeches of the categories “retirement and identity in Parkinson disease”; “the incompatibility between the desire and the capacity to work”. The *off* fluctuations, the freezing, and the dyskinesia exhibit statistically significant associations to the workforce unavailability as primary factors for early retirement in PD cases, being more difficult to accept this moment, generating special repercussions in the emotional instability<sup>(12)</sup>.

A recent systematic review about work capacity in PD found that the requests to adjust functions of many PD workers were not always attended. Results demonstrated that employees with chronic diseases before retirement could have accentuated signs and symptoms after this process, due to the exacerbation of psychological and emotional factors, especially in a neurodegenerative disease as PD; that produces harmful effects on the work capacity, and it is associated with high costs and great loss of individual gains throughout life<sup>(13)</sup>.

The work capacity and independence are two important activities in daily life and of particular concern for people with PD, who wish to know for how long their capacity will last since the diagnosis<sup>(14)</sup>. Thus, as reported by participants in our study, disease changes also interfere in workers’ ability to perform their activities according to what is expected from them.

Another retirement study revealed the negative impact of non-communicable chronic diseases in a population at active age with a high percentage of early retirements, besides creating social costs for the individuals and their families<sup>(15)</sup>. This fact is verified by participant’s speeches when they feel lacking structure with the imposition to retire still at productive age, destroying professionals’ dreams and reducing their the social importance.

When analyzing our study results, we verify that economically active workers are absent from the job market earlier each time, due to physical and emotional changes caused by health problems. In the PD case, signs and symptoms of the pathology were mentioned by participants as unfeasible for them to stay at work. This reveals a significant issue, of how much withdraw from labor activities causes social and economic repercussions, affecting the retired person with physical and psychological losses. About the government, it lays on it the public health and welfare costs once the person stops working and contributing, becoming dependent on welfare benefits<sup>(16)</sup>.

Due to its characteristics, Parkinson disease results in motor changes that are chronic and

degenerative, and most likely that such difficulties will evolve over time<sup>(2)</sup>. As reported by one participant from our study, the delay imposed by the disease is a unaccepted disability in the working world centered in productivity. The incompatibility between the desire to do and the capacity to perform leads people with PD to be referred to early retirement. The speeches still reveal physical changes as limiting the exercise of professional activities, using successive medical leaves until culminating in retirement.

Corroborating with the results of our study, a study investigated and compared health perception and quality of life of active and away workers. The authors identified that people who were away had worse quality of life in the functional capacity, physical aspect, pain, general health state, social aspect, emotional aspect and mental health domains when compared to active workers. It still reveals that worse perception of health and quality of life decreases the number of possibilities into the working world<sup>(17)</sup>. These results allow the reflection about the impact of work withdraws and, the importance of retirement studies caused by non-communicable chronic diseases.

In some cultures, like ours, the professional role is one of the pillars of self-esteem, identity, and sense of utility, once work is one of the fundamental aspects of the individual identity, as the person's name, gender, and nationality, linking the present to the future<sup>(7)</sup>. We found in participant's speeches that disability retirement causes negative emotional impact in people with Parkinson. The sudden rupture with work and the interruption of future projects causes mental suffering to these people, who need to learn how to adapt to new physical conditions while losing social functions, as their working life.

The speeches demonstrate that the person who experiences retirement due to PD is unplugged from the working world and needs to live with the new health diagnosis and to comprehend the expectation of a future with the disease.

When getting closer to the retirement time, people experience ambiguous feelings: of accomplished duty and freedom, but also the sadness and uncertainty regarding the future. The process of preparation for retirement should start with the introduction of the individual's working life, as it constitutes a challenge for the field of human management, especially in practices aiming at worker's well-being<sup>(8)</sup>. Thus, Programs for Retirement Preparation (PRP) are foreseen in the Elderly National Policy and the Elderly Statute, as health promotion actions and quality of life. This program has as primary goal to prepare people for retirement, to clarify doubts, to help to discover new activities, to deal with finances and healthcare<sup>(18)</sup>.

Results from a study conducted with people that retired due to service time without having a preparation pointed the same difficulties of adaptation mentioned in the speeches of our study. The study also revealed the suffering experienced at the rupture moment with the productive environment<sup>(19)</sup>.

Considering the unexpected retirement, health professionals can assist in this preparation, and they can increase the health and wellbeing potential of the person after disconnecting from work. Within the actions for this situation, the support to these people, helping them to look for personal transformation to cope with this step, is noted<sup>(20)</sup>. The professional should contribute to maximizing the potentialities of people with PD, stimulating to discover new abilities for healthy living, even when experiencing a chronic health

condition.

## CONCLUSION

Within the non-communicable chronic diseases, PD deserves attention due to its characteristics. Our study allowed the comprehension of the relationship of work and Parkinson disease, revealing coping dimensions of the experience of living with the disease and, in this case, the rupture process with work until the disability retirement.

Besides physical changes, the PD generates psychological complications that can be intensified with the process of early retirement, especially when the adequate accompaniment and prior preparation to experience such moment is missing.

Therefore, we found that early retirement is an aspect that should be deepened in future studies, especially involving nursing and PD. Thus, the study contributes with nursing to (re) think the professional practice aimed at the person with Parkinson disease, especially during active age. We found dissatisfaction of people with the early retirement and the need for actions to re-signify the retirement process; developing measures to allow the permanence of the person with DP in the work market. These measures can involve vocational rehabilitation, reduction of the workload or, interventions intended to propitiate a transition between the change of roles in a search for a productive living, aiming to minimize the suffering of people with PD.

Considering the lack of national scientific literature about the theme disability retirement and PD, we reaffirm the importance of studies in this field, especially those conducted by health professionals, considering the need to look at the subject's integrality, which disinsertion of work interferes in a decisive manner about one's health condition.

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