



Journal of Nursing

Revista de Enfermagem

UFPE On Line

ISSN: 1981-8963

ORIGINAL ARTICLE

INTERRUPTION OF THE DAILY LIFE IMPOSED BY PARKINSON'S DISEASE: ELDERLY 'S PERSPECTIVE WITH PARKINSON

A INTERRUPTÃO DO COTIDIANO IMPOSTA PELA DOENÇA DE PARKINSON: PERSPECTIVAS DE IDOSOS PARKINSONIANOS

LA INTERRUPCIÓN DEL COTIDIANO IMPUESTA POR LA ENFERMEDAD DE PARKINSON: PERSPECTIVAS DE ANCIANOS COM PARKINSON

Alexei Rodrigues Gomes¹, Donizete Vago Daher², Thais Cordeiro Fonseca³

ABSTRACT

Objective: to know the daily life of elderly patients with Parkinson's disease (PD) after insertion in an educational group. **Method:** A qualitative descriptive study conducted in 2008, through interviews with fifteen subjects of the Parkinson Group and included in the Interdisciplinary Program of Geriatrics and Gerontology (PIGG/UFF) in Niterói / RJ. The procedures of data analysis was carried out through thematic analysis. The Research Ethics Protocol 166/06 approved the research project. **Results:** After analyzing the following categories emerged << The link between the physician and the group of Parkinson >>, << The group and scenario Self-knowledge and Sharing >>, << Beyond Parkinson Group >>, << Limitations generate feelings of worthlessness >>; << How do I see the day of tomorrow? The ambivalence of feeling prevails. >> **Conclusion:** daily life is marked by gradual disruption in daily activities with the space group of reorientation of dealing with losses and limitations. **Descriptors:** Elderly; Parkinson's disease; Self-Help Groups.

RESUMO

Objetivo: conhecer o cotidiano de idosos portadores de Doença de Parkinson (DP) após inserção em grupo educativo. **Método:** estudo qualitativo-descritivo, realizado no ano de 2008, por meio de entrevistas com quinze sujeitos do Grupo Parkinson e que estavam inseridos no Programa Interdisciplinar de Geriatria e Gerontologia (PIGG/UFF) em Niterói/RJ. Os procedimentos de análise dos dados efetivaram-se pela análise temática. O projeto de pesquisa foi aprovado pelo Comitê de Ética em Pesquisa, Protocolo 166/06. **Resultados:** após a análise emergiram as categorias << O elo entre o médico e o grupo de Parkinson >>, << O grupo é cenário de autoconhecimento e de Compartilhamento >>, << Para Além do Grupo Parkinson >>, << As limitações geram sentimentos de inutilidade >>; << Como vejo o amanhã? A ambivalência de sentimento prevalece >>. **Conclusão:** o cotidiano é marcado por gradativa interrupção nas atividades de vida diária sendo o grupo espaço de reorientação do lidar com as perdas e limitações. **Descritores:** Idoso; Doença de Parkinson; Grupos de Autoajuda.

RESUMEN

Objetivo: conocer el cotidiano de ancianos portadores de Enfermedad de Parkinson (EP) después de la inserción en grupo educativo. **Método:** estudio cualitativo-descriptivo realizado en el año de 2008, por medio de entrevistas con quince sujetos del Grupo Parkinson e inseridos en el Programa Interdisciplinar de Geriatria y Gerontología (PIGG/UFF) em Niterói/RJ. Los procedimientos de análisis de los datos se efectivó por el análisis temático. El proyecto de investigación fue aprobado por el Comité de Ética en Investigación, Protocolo 166/06. **Resultados:** después del análisis surgieron las categorías << El enlace entre o médico y el grupo de Parkinson >>, << El grupo es escenario de autoconocimiento y de Comparto >>, << Para Más allá del Grupo Parkinson >>, << Las limitaciones generan sentimientos de inutilidad >>; << Cómo veo el mañana? La ambivalencia de sentimiento prevalece >>. **Conclusión:** el cotidiano es marcado por gradual interrupción en las actividades de vida diaria siendo el grupo espacio de reorientación de lidar con las pérdidas y limitaciones. **Descritores:** Anciano; Enfermedad de Parkinson; Grupos de Auto-Ayuda.

¹Nurse, Master degree, Master Course Professional Care, Nursing School Aurora de Afonso Costa, Fluminense Federal University /UFF. Niterói (RJ), Brazil. E-mail: alexeirg@ig.com; ²Nurse, Doctorate Professor, Medical-Surgical Nursing Department, Nursing School Aurora de Afonso Costa, Fluminense Federal University/UFF. Niterói (RJ), Brazil. E-mail: donizete@predialnet.com.br; ³Nursing Student, Undergraduate and Graduate Nursing Course, School of Nursing Aurora de Afonso Costa, Fluminense Federal University/UFF. Scholarship PIBIC/UFF - 2011/2012. Niterói (RJ), Brazil. E-mail: thaisfoonseca@hotmail.com

INTRODUCTION

Within a priority bio-gerontologic view, aging is a dynamic and progressive process in which there are morphological, functional, biochemical and psychological changes that may determine increased vulnerability and increased incidence of pathological processes that eventually lead to death.¹ Each individual experiences the aging of a peculiar or unique way. Thus, aging is a process of life and as such it carries old age, but does not end it.²

The organic transformations indicate that the literal sense of the passage of time are constant through social referrals such as color of hair, wrinkles, postmenopausal, modified posture, slower reflexes, as a relevant transformer factor of self-image of the elderly as it may start important emotional disorders.³

The satisfaction or not with life will depend on biological, psychological, social and environmental factors, which makes each individual to experience the different stages of aging with more or less success.⁴ The increase in life expectancy in developed countries, including Brazil, may also mean increasing the number of older people with chronic diseases and the consequences related to them. Among them it is Parkinson's Disease (PD), now also known as Neurological Movement Disorder (NMD), corresponding to 40-75% of all causes of parkinson.⁵ Thus, Brazil is moving gradually towards a listing increasingly aged population, a fact that requires the health system to suit regarding social policies, especially those geared to meet the growing demands in the areas of health, social security and welfare.⁶

Parkinson's disease is chronic and progressive and involves the basal ganglia of the nervous system. Thus, results in disturbances in muscle tone, abnormal postures and involuntary movements.⁷ The most common and significant motor symptoms of Parkinson's disease are muscle rigidity, resting tremor, bradykinesia, and postural instability, and the diagnosis is based on neuropathological findings: degeneration and loss of pigmentation of the neurons of substantia nigra (pars compacta) and intraneuronal inclusion bodies (Lewy bodies) in the substantia nigra.⁸

Considering that the resting tremor is characteristic, action tremor, re-emergent tremor and orthostatic tremor may also occur in Parkinson's disease. Symptomatic treatments are quite effective in early disease, but may be complicated by the

appearance of motor fluctuations and dyskinesias in more advanced diseases.⁹ Although Parkinson's disease is characterized as a frequent disorder whose commitment can involve any individual or age group, it is observed upon global epidemiological findings, that there is a higher frequency of cases among male individuals, aged above 60 years old.¹⁰

Living with a chronic disease such as Parkinson's is a complex process that requires changes in habits and costumes.¹¹ Modifying the routine life of the elderly in the diagnosis of a chronic non-communicable disease such as Parkinson's requires a special family support and care planning patients requires careful analysis of signs and symptoms, compromises and limitations, which must be observed during diagnostic assessment by health professionals. In this sense, the implementation of nursing interventions aimed at improving mobility, maintain independent functions, helping patients to cope with the illness and support for activities of daily living (ADLs).

The daily life of elderly patients with PD tends to be compromised due to the limitations which the disease imposes and may arise, for example, depressive disorders. We need further study and analysis on this injury and its implications and even demystify social constructs related to it.

The foregoing and to guide the construction and understanding of this study, the following guiding questions are outlined: What are the limitations imposed on daily life of the elderly with PD? Do strategies of health education as educational groups contribute to improving the quality of life of patients with PD? We sought, in this sense, knowing the daily lives of people with Parkinson's disease in an attempt to lift the restrictions imposed on the carrier of the disease.

This study is justified by the growing demand for proven elderly in Brazil and the fact that this stage of life come, most often accompanied by chronic diseases such as Parkinson's disease.

The aim is thus to contribute to the expansion of knowledge in the field of Gerontogeriatric Nursing and as a possibility of awareness of the health professionals and in particular the nurse to favor or perform a contextualized and humanized care to frail elderly (dependent or not) by Parkinson's disease. The guiding purpose of the actions of the health professionals should therefore be attempting to become the elderly with the PD independent as possible. Thus, this subject,

Gomes AR, Daher DV, Fonseca TC.

even carrying a chronic aggravation, he can enjoy the best moments of his aging process.

OBJETIVE

- To know the daily life of elderly patients with Parkinson's disease (PD) after insertion in an educational group.

METHOD

Study of qualitative-exploratory type, with elderly participants of the Interdisciplinary Program of Geriatrics and Gerontology at the Federal Fluminense University (PIGG / UFF).

The sample consisted of fifteen elderly who were carefully selected based on having a diagnosis of Parkinson's disease, being members of the group for over a year, both sexes and without cognitive impairment that would prevent them from responding to the interview.

The instrument for data collection were semi-structured interviews conducted before or after the group's activities, and procedures of data analysis was carried out through thematic analysis.

The Ethics Committee of the Faculty of Medicine of the UFF approved the research project, number 166/06 Protocol.

RESULTS

♦ Characteristics of the participants

Regarding age, most were more than 60 years old and the predominant age group was 62-66 years old. It was proved that the majority is female, is "housewife" and has completed elementary school. PD affects more men than women, but the aging of the population entered a demographic change, the majority of the elderly population today is women. The elderly are the fastest access to the groups to self-care.¹³ This fact may have contributed to the prevalence of PD in this older group.

With the approach of the discourses, themes emerged which are described below:

• The link between the physician and the group of Parkinson

When they were asked about the type of participation in the program, the respondents reported that this was given by the doctors of the Neurology Service of the University Hospital Antonio Pedro (HUAP), which after consultations and examinations, verified Parkinson's disease and so they were asked to enroll in the Interdisciplinary program of Geriatrics and Gerontology at the Fluminense Federal University (PIGG / UFF) and more specifically, the activities of Parkinson group.

Interruption of the daily life imposed by parkinson's...

The following statements show this trajectory:

I was accompanied by neurologists at University Hospital Antonio Pedro who told me about the group. I came, and I really liked it. It has already been 2 years. (João); I came here for guidance of my neurologist whom I trust very much. This was 1 ½ years ago. I feel safe here, it is my support group, and I do not only come when I'm really bad. (Irene)

• The group and scenario Self-knowledge and Sharing

The groups that carry out activities with the elderly , called GTIs , have a key role in achieving and expanding quality of life of this social group , social movement of GTIs shows up as an alternative project under construction on the various crises of contemporary society. Combating social exclusion in old age, redefining the spaces of citizenship, the GTIs are forms of collective action, in partnership with other social actors, created by those who are in the "third age ".¹⁴

The group does not have the sole purpose of improving the motor conditions of the elderly with parkinson. Due to the interpersonal relationships established in that scenario, the meetings will also be required social character. To know and meeting other people with PD and other neurodegenerative parkinsonian syndromes and with families and caregivers can help to combat feelings of anger, isolation and despair.⁵

The statements give a true picture of the role of the Parkinson's Group in their lives:

I feel good because I see other people with the same disease. (Azaléa).
The group passes knowledge and does activities [...] it has changed the way of recognizing my limits and relationships with the family. (João)
My daily life has changed with this disease that makes me very sad, but here in the group I feel better. (Júlia)

• Beyond Parkinson Group

Many of the interviewees reported that physical activities are not limited to those proposed by the Parkinson's Group staff because for them the group awakened to the importance of other activities "extra-group" as: gymnastics, aerobics, walking, trips among other as indicate the lines of

I went to get exercise more with walks, even if small ones, they help me a lot. "(Ernesto)
In addition to the exercises here that I really like, I still do gymnastics and weightlifting. The group awoke to other activities and I was because of Gugu (Maria)
I do physiotherapy and hydrotherapy. Also I like going out, but I depend on other people

Gomes AR, Daher DV, Fonseca TC.

Interruption of the daily life imposed by parkinson's...

to carry out activities that both enjoy.
(Carlos)

● **Limitations generate feelings of worthlessness**

In most speeches appeared to express terms or feature limitations, losses and feelings of worthlessness.

The disease took a turn in my life too big, I had to change everything in my house since I was a dynamic person and now I'm not any more. I have difficulty to take care of myself. It is not the tremor that bothers me but the balance is very bad. Having to walk with a cane, being that I was a person who did not like anyone "walked" behind me.
(Rosa)

What bothers me a lot is the forgetfulness and the limitations of physical activities such as soccer, beach tennis, I can not practice any more. (João)

I wish I could just go out alone, but my kids do not leave me now, I'm insecure, shaky and this saddens me. They need to help me to dress up, to eat. I feel useless and dependent. "(Margarida)

How do I see the day of tomorrow? The ambivalence of feeling prevails...

The feelings expressed by the subjects externalized between the welfare that was conquered and enlarged with the coexistence in the group and sorrow for living with limitations produced by the disease.

I hope to appear new medications and cure for Parkinson's disease and that the cells - stem are the 'key' of the problem. But coming to the group makes us lean and not lose heart "(Rosa)

I have a view to improving and could return to my activities as swimming, my football. All my stuff. (Aristides)

DISCUSSION

Parkinsonian signs such as tremor, bradykinesia, rigidity and postural instability were observed in the participants of the study. Most need some kind of assistance to sit and get up from the chair. Decreased mobilization of elderly restricts them in managing their lives, in their autonomy.¹⁵

Some of the participants "take a nap" during activities, but not for lack of interest, but probably by sleep disorder fairly common occurrence in the elderly with parkinson.⁵ This disorder is very common in these patients and cover a wide range of symptoms including: difficulty initiating sleep, frequent awakenings during the night, sudden onset of sleep during daytime activities and night terrors. Thus, the activities are not generating physical wear but promoting wellness, proven

by the attendance and interaction among participants and responsables.

It was evident that the medical professional plays a strong role in the health - disease process of the elderly individuals with PD. The annular configuration of the doctor-patient relationship, in this case, proceeds from the diagnostic and therapeutic protocol implemented. But other professionals were reminded by the subjects as fundamental attendance for joining the group.

The relevance of working with PD clients through educational processes aimed at deconstructing stereotypes relating to restrictions imposed by the PD was proven. Thus, expanding the supply of group activities that contribute to minimizing frames of melancholy and extend the quality of life in elderly parkinsonian should be a challenge to public health.

The Parkinson Group is a significant change in the lives of the elderly. This goes beyond a physical therapy group for the restoration or preservation of motor movements hampered by the PD. The weekly meetings are in an environment of love, care and respect, with the perfect interaction between participants and professionals, going to have fundamental psychosocial developments, acting thus as a living space that resizes the exclusion of the elderly and in particular, the elderly patients with PD.

In the particular case scenario of the study, the Parkinson's Group now has fundamentally important in the search for social relations with regard to ward off possible depressive conditions for the preservation of motor activities and expansion of quality of life. These perspectives were present in the subjects' speech when asked how they feel after the insertion in the group.

The group does not behave, for the subjects, only as a space that seeks improvement in motor conditions, as already mentioned. Due to the interpersonal relationships established, it also acts as a space for building new relationships, ie, has a character redemption of social interrelations that had committed the presence of the disease.

The inclusion of older people with chronic diseases in groups of living also contributes to widen the search activities beyond those planned by the group, thus contributing to the socialization, self-esteem and redemption of regaining the quality of life of them. In this regard it is noted that the draft elderly groups have contributed to the revision of the understanding of the concept of health and disease, the construction of the dream of

Gomes AR, Daher DV, Fonseca TC.

healthy aging and at the same time, it has been constituted in learning channels, motivation, education for life and citizenship.¹⁴

Through the reports, we found that Parkinson's disease brings limitations that directly affect activities of daily living (ADLs) of sufferers. Adaptation to the new lifestyle, with respect to the limitations and difficulties of day-to-day, is revealed through an awareness of the need for greater self-care.¹¹

By analyzing the relationship between the modes of occupation, it became evident that all subjects had their everyday modified after the onset of illness. It is important to highlight the disruption of business activities triggered by the progression of symptoms caused many moments of melancholy and insecurity.

During the physical activities offered, the subject's limitations of exercises related to motor coordination were observed, but everyone always tried to perform them. The ambivalence of feelings was present in most of the speeches. Talk about a hopeful tomorrow, with an improved prospects and find an effective drug therapy while they are concerned about the future and the possibility of worsening of dependence.

CONCLUSION

The Brazilian population is rapidly aging process, life expectancy has been increasing in recent decades. So, it is important to study this population and priority in search of overcoming social prejudices that still prevail in relation to the elderly. Stereotypes and myths related to aging are updated daily, a challenge to be overcome by modern Western societies.

With increased life expectancy, increased concomitantly higher incidence of disease in this group of people, eg, chronic non-communicable diseases (NCDs), inserted them PD.

In all the speeches, it was evident that the advent of disease brought changes to the routine of daily activities. In various speeches, it can be proved that individuals living with fears and stereotypes related to aging and such other related Parkinson's disease were aggregated. Thus, feelings of worthlessness and dependency, limitations imposed by the disease, were reported by the subjects who undertake their daily activities, previously carried out independently. These limitations ultimately affect directly the quality of life, which often leads to feelings of fear, discouragement and unrest.

Interruption of the daily life imposed by parkinson's...

This shows the need for qualified professionals to care for those specific subjects. As the nurse has in its cast of professional activities to provide, the more they are updated direct care professionals, the better the quality of care provided to patients and their caregiver network, fact checking, therefore greater visibility to the profession.

The coexistence groups, similar to what happens in Parkinson Group PIGG / UFF can reframe the lives of individuals living with the injury, contributing to the reconquest of a healthier life. These groups offers up multidisciplinary care and the nurse is able to compose with other professional teams, thus overcoming the one-sidedness of care. This professional also has the possibility to act as health educators with the participants of the group and their families.

The elderly who participated in the Parkinson group built a solid network of relationships and emotions, generating changes in their lives and reinterpretation. Coexistence groups worked by multidisciplinary teams function as spaces for building networks of sharing experiences similar conditions, resulting in beneficial effects for all who participate.

REFERENCES

1. Freitas EV. Demografia e Epidemiologia do Envelhecimento. In: BARROS, Myriam Moraes L. de. Envelhecimento, cultura e transformações sociais. PY, Lígia et al. Tempo de envelhecer: percursos e dimensões psicossociais. Rio de Janeiro: Ed. NAU; 2004.
2. Sant'Ana JAL, Brêtas ACP. O envelhecimento para militares que serviram no exército brasileiro. Acta paul enferm [Internet]. 2011 [cited 2013 Feb 20];24(4):5006. Available from: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0103-21002011000400009&lng=en.
3. Cruz RDC, Ferreira MA. Um certo jeito de ser velho: representações sociais da velhice por familiares de idosos. Texto contexto - enferm [Internet]. 2011 Mar [cited 2013 Feb 20];20(1):144-5. Available from: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0104-07072011000100017&lng=en.
4. Fabrício SCC, Rodrigues RAP. Percepção de idosos sobre alterações das atividades da vida diária após acidentes por queda. R Enfermagem UERJ; [Internet]. 2006 [cited 2013 Feb 20];14 (4);531-7. Available from: <http://bases.bireme.br/cgi-bin/wxislind.exe/iah/online/?IscScript=iah/ia>

Gomes AR, Daher DV, Fonseca TC.

Interruption of the daily life imposed by parkinson's...

[h.xis&src=google&base=BDENF&lang=p&nextAction=lnk&exprSearch=14482&indexSearch=ID](http://www.scielo.br/scielo.php?script=sci_arctext&pid=S1414-81452010000400003&lng=en&nrm=iso)

5. Barbosa MT. Doença de Parkinson em Idosos. In: SALDANHA e CALDAS. A Saúde do Idoso: a arte de cuidar. 2002.

6. Brasil. Ministério da Saúde. Secretaria de Atenção à Saúde. Departamento de Ações Programáticas e Estratégicas. Atenção à saúde da pessoa idosa e envelhecimento. Área Técnica Saúde do Idoso. - Brasília [Internet]. 2010 Mar [cited 2013 Feb 20];44 p.: il. - (Série B. Textos Básicos de Saúde) (Série Pactos pela Saúde 2006, v. 12). Available from: <http://portal.saude.gov.br/portal/arquivos/pdf/volume12.pdf>

7. Marsh MDL. Neuropsychiatric Aspects of Parkinson's Disease. Psychosomatics [Internet]. 2000 Mar [cited 2013 Feb 20];41:15-23. Available from: http://www.cognition.org/Psych_PD.pdf

8. Murray, G. Progressive aphasic syndromes: clinical and theoretical advances Current Opinion in Neurology. Degenerative diseases [Internet]. 2002 Mar [cited 2013 Feb 20];15(4):409-13. Available from: http://journals.lww.com/co-neurology/Abstract/2002/08000/Progressive_aphasic_syndromes_clinical_and.2.aspx

9. Kapil DS, Clinical aspects of Parkinson disease Current Opinion in Neurology. Movement disorders [Internet]. 2002 Mar [cited 2013 Feb 20];15(4):457-60. Available from: http://journals.lww.com/co-neurology/Abstract/2002/08000/Clinical_aspects_of_Parkinson_disease.9.aspx

10. Tavares GPC, Torquato IM, Dantas, MAS et al. Frequência de quedas e identificação dos fatores de risco em portadores de parkinsonismo primário. J Nurs UFPE on line [Internet]. 2012 July [cited 2013 Feb 20];6(7):1530-8. Available from: <http://www.revista.ufpe.br/revistaenfermagem/index.php/revista/article/view/2782>

11. Navarro-Peternella FM, Marcon SS. A convivência com a doença de Parkinson na perspectiva do parkinsoniano e seus familiares. Rev Gaúcha Enferm (Online) [Internet]. 2010 Sept [cited 2013 Feb 20];31(3):415-22. Available from: http://www.scielo.br/scielo.php?script=sci_arctext&pid=S1983-14472010000300002&lng=en.

12. Minayo MCS. O desafio do conhecimento: pesquisa qualitativa em saúde. 8th ed. São Paulo: Hucitec; 2004.

13. Daher DV, Debona, KV. Reelaborando o viver: o papel do grupo no cotidiano de mulheres idosas. Esc Anna Nery [Internet]. 2010 Dec [cited 2013 Feb 20];14(4):670. Available from:

http://www.scielo.br/scielo.php?script=sci_arctext&pid=S1414-81452010000400003&lng=en&nrm=iso

14. Portella MR. Grupos de Terceira Idade: a construção da utopia do envelhecer saudável. Passo Fundo: UPF; 2004

15. Roper N, Logan W, Tierney AJ. O modelo de enfermagem: baseado nas atividades de vida diária. Lisboa: Climepsi; 2001. In Lopes MVO, Araújo MFM, Moraes GLA. Avaliação do grau de dependência nas atividades de vida diária em idosos da cidade de Fortaleza - Ceará. Acta Paul Enferm [Internet]. 2006;19(2):201-6. Available from: http://www.scielo.br/scielo.php?script=sci_arctext&pid=S0103

Submission: 2013/05/12

Accepted: 2014/03/23

Publishing: 2014/05/01

Corresponding Address

Thais Cordeiro Fonseca
Bolsista do Programa de Iniciação Científica - PIBIC/UFF
Universidade Federal Fluminense
Rua Visconde de Tocantins, 29 apto 306 - Méier - Rio de Janeiro - RJ
CEP: 20775-070 — Rio de Janeiro (RJ), Brazil