

Parkinson's disease impact on computer use. A patients' and caregivers' perspective





Objectives:

The purpose of the study is to evaluate Parkinson's disease (PD) impact on computer use as this is experienced by the patients and their caregivers.

These are preliminary data for the EU Horizon 2020, MAMEM project (Multimedia Authoring and Management using your Eyes and Mind).

Background:

Motor and non-motor symptoms of PD affect the ability to use computers. Although patients consider computer use as an important part of their everyday life they face many operational difficulties.

Methods:

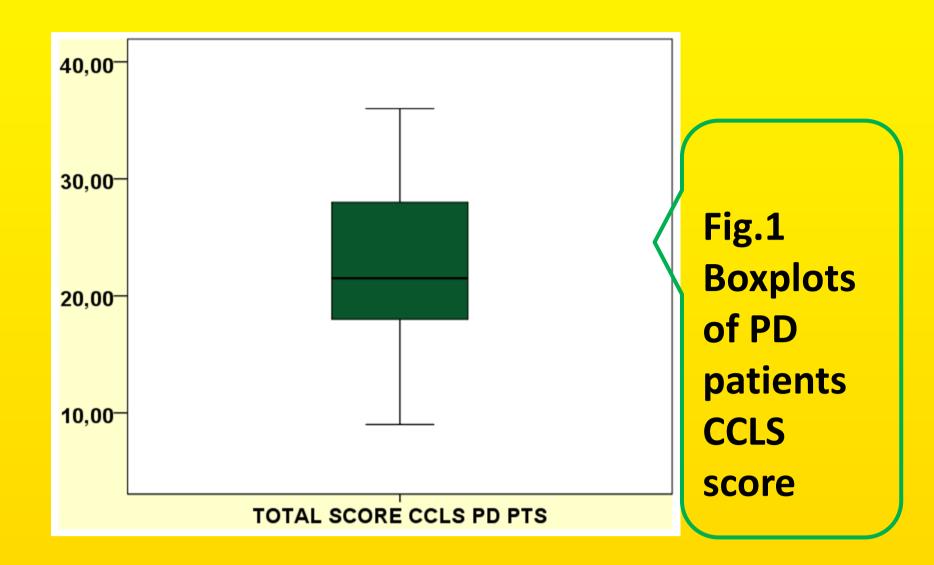
Fifty PD patients, with a mean age of 59.1±SD 8.05 years were included in the study. Their mean disease duration was 8.96 ± SD 5.5 years and median stage was 2 [range1-4]. PD patients uses and difficulties with the computer were explored by means of a structured interview. Using the most pertinent data from this interview we designed two quantitative scales one referring to the contribution of the computer in various aspects of social life (CCSL), with 9 items, each item scoring on a scale from 1(not important) to 5 (very important), and the other exploring the disease impact on various aspects of computer operation (DICOS), with 11 items (single item score ranged from 1: no effect to 5 :maximum effect). Twenty caregivers (spouses) were interviewed using the same questionnaires as the patients, adapted for completion by proxy. Patients' questionnaires are presented in Appendix.

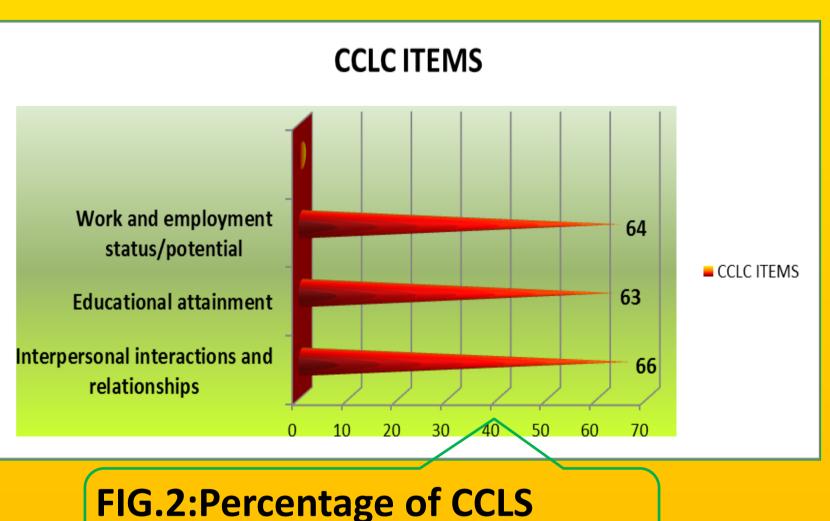
Statistical Analysis: Reliability of both scales was assessed by means of Cronbach's alpha coefficient. Caregivers' scale scores were compared to those of their patients by means of the t test for independent samples.

Results:

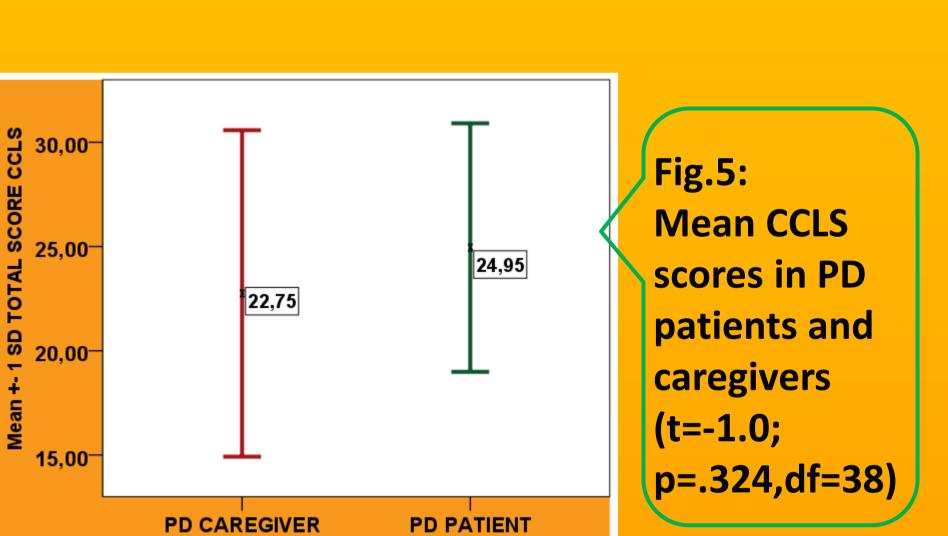
PD patients reported having a mean 13.6 (SD= 9.1) years of computer experience and a mean daily use of 3.9 (SD=2.4) hours. Reliability analysis for both scales yielded satisfactory results. Cronbach's alpha was 0.76 for CCLS and 0.92 for the DICOS, while item to total correlations ranged from 0.224 (item:emotional wellbeing] to 0.649 for CCLS and from 0.436 to 0.772 for DICOS.

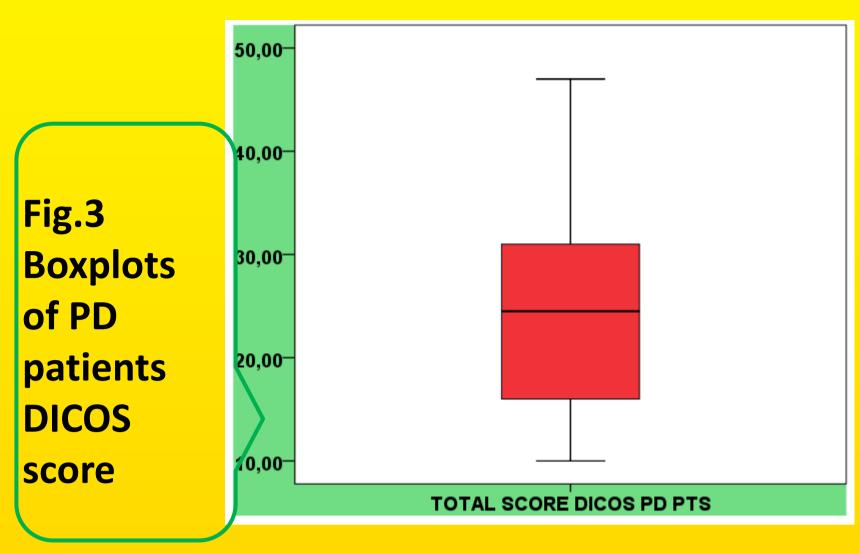
The mean total score of PD patients on the CCSL scale was 22.7±6.9,(figure 1).Single items that scored high were relevant to interpersonal interaction, education, work and employment. (figure 2). The DICOS scale yielded a mean total score of 24.7± 10.0 (figure 3) .Single items that had a significant impact on the whole score were speed of computer operation and accuracy of performance, (figure 4). Caregivers' mean scores on the CCSL and DICOS scales were comparable to those of the patients (figure 5 & 6).

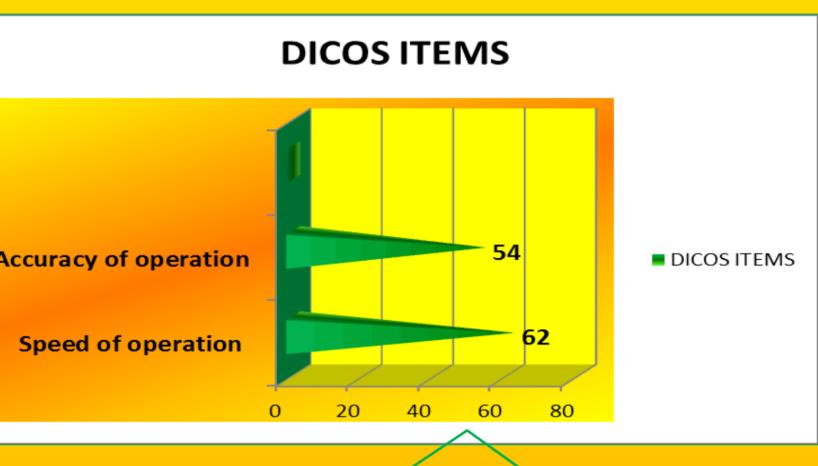




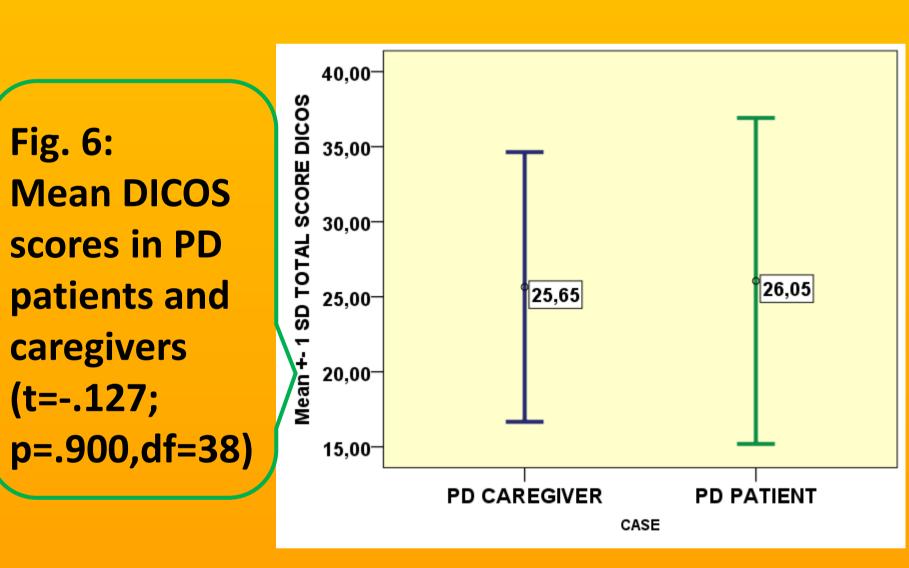
items with high scores











Conclusions: Our preliminary results show that PD patients and their caregivers regard computer use as important aspect of their lives. However loss of speed and accuracy are significant obstacles in computer operation. This information is important for the development of innovating technology helping patients to overcome their specific disabilities.

APPENDIX

How important is the contribution of computer use n in the following aspects of your life?						
CCLS Items	1- not important at all, 5- very important)					
1.Interpersonal interactions and relationships	1 2 3 4 5					
2.Close, intimate relationships	1 2 3 4 5					
3.Educational attainment	1 2 3 4 5					
4.Work and employment status/potential	1 2 3 4 5					
5.Participation in desired community, social and civic activities	1 2 3 4 5					
6.Autonomy and self-determination (making decisions)	1 2 3 4 5					
7.Fitting in, belonging, feeling connected	1 2 3 4 5					
8.Emotional well-being	1 2 3 4 5					
0 Occasilly handled	1 2 2 4 5					

How does your current physical condition affect the following computer use aspects?						
DICOS items	No effect	Mildly	Moderately	Substantially	Completely	
1.Comfort	1	2	3	4	5	
2.Independence	1	2	3	4	5	
3.Satisfaction	1	2	3	4	5	
4.Pain	1	2	3	4	5	
5.Speed of operation	1	2	3	4	5	
6.Fatigue	1	2	3	4	5	
7.Accuracy of operation	1	2	3	4	5	
8.Endurance	1	2	3	4	5	
9.Effectiveness	1	2	3	4	5	
10.Ease of use	1	2	3	4	5	
11.Enabling privacy	1	2	3	4	5	