RAISE AWARENESS FOR PARKINSON'S DISEASE AND TELEREHABILITATION: A TREATMENT OFFER TO FACE UP PANDEMIC

Rehabilitation Neurology Division
Maugeri Clinical Scientific Institutes
THE INVOLVEMENT OF THE PSYCHOLOGIST IN THE TELEREHABILITATION PROGRAMMES

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STATE – OF – ART OF THE PSYCHOLOGIST IN TELEHEALTH

Involvement of the psychologist in telehealth - telerehabilitation of:

• Chronic pain patients  (Cranen et al., 2011)

• Heart failure patients  (Piotrowicz et al., 2016)

• Parkinson’s disease patients  (Pretzer-Aboff et al, 2015; Swallwell et al., 2018)
PARKINSON’S DISEASE (PD)

Motor symptoms

Non-motor symptoms

NEUROPSYCHIATRIC SYMPTOMS

- Magnify disability
- Increase the need for supervision
- Affect emotional aspects of the relationship with a caregiver

(Mosley et al., 2017)
NON-MOTOR SYMPTOMS

**Neuropsychiatric Symptoms**

- Sexual behaviour impairments
- Cognitive decline
- Depression, Apathy
- Sleep disturbances
- Impulse dyscontrol
- Anxiety
- Psychosis

(Grover et al., 2015; Pfeiffer, 2016; Mosley et al., 2017)
PD PSYCHOLOGICAL INTERVENTION

EVALUATION

- Emotional support
- Encourage acceptance and adaptation
- Contain symptoms
- Facilitate compliance
- Change risky behaviors
- Cognitive stimulation

INTERVENTIONS

OUTCOME

Improve QUALITY OF LIFE

The involvement of the psychologist in the telerehabilitation programmes
“The unpaid person who primarily cares for the patient because of emotional ties regardless of any family relationship”

It’s not possible to consider the patient without her/his caregiver

What about chronicity?

(Rossi et al., 2001; Vidotto et al., 2010)
PD CAREGIVER RESPONSABILITIES

- Personal care assistance
- Medication administration
- Mobility assistance
- Social and emotional support
- Financial support
- Daily living assistance

- Less leisure or social activities
- Physical and mental fatigue
- Lower QUALITY OF LIFE

(Mosley et al., 2017; Smith et al., 2019)

The involvement of the psychologist in the telerehabilitation programmes
PD CAREGIVER CONSEQUENCES

- Depression
- Stress
- Social problems
- Health problems
- Sleep disturbances
- Economic problems

(Happe et al., 2002; Graham et al. 2006; Schrag et al., 2006; Martinez-Martin et al., 2012)
"The extent to which caregivers perceive that caregiving has had an adverse effect on their emotional, social, financial, physical and spiritual functioning" (Zarit & Zarit, 1986)

- Frequent hospitalizations
- Lower Quality of Life
(Kuzuya et al., 2011; Mohamed et al., 2010)
WHY TAKE CARE OF THE CAREGIVER?

Influence on patient’s acceptance of the disease

Influence on patient's compliance

Compensation for economic and structural deficiencies

Reasons directly related to the patient
THE PSYCHOLOGIST FOR PD CAREGIVER

EVALUATION

Emotional support
Reduce subjective burden/strain
Increase disease knowledge
Underline importance of social support
Encourage health care

INTERVENTIONS

OUTCOME

Improve QUALITY OF LIFE
TELE SUPPORT FOR THE CAREGIVER

✓ Review of telehealth tools and interventions to support family caregivers: satisfaction and improvements in caregivers’ outcomes (Chi & Demigris, 2014)

✓ PD caregiver telesupport group: positive feedback (Shah et al., 2015)

✓ Telehealth intervention: reduced dementia caregiving-burden (Lindauer et al., 2019)
TELEMEDICINE

Activities in ICS Maugeri (Veruno):

- VAMP* – Disease management*
- TELEPARK
- REPORT
- 5x1000
VAMP: THE ROLE OF THE PSYCHOLOGIST

360 ° professional assistance for disease management

- Psychological and cognitive assessment interviews
- Support interviews
TELEPARK: THE ROLE OF THE PSYCHOLOGIST

- Psychological and cognitive assessment interviews
- Continuing the psychological intervention started as soon as enrolled to deal with the emotional discomfort and problems related to the acceptance/management of the disease (for patient and caregiver)
REPORT: THE ROLE OF THE PSYCHOLOGIST

- Assessing the presence of emotional disorders, the quality of life and the cognitive functioning of the patients
- Assessing caregiving-related strain in caregivers
- Supporting by telephone the caregivers of patients that follow the home rehabilitation program
Assessment of caregiver’s role during telerehabilitation of patient with Parkinson Disease and sleep disorders.

To study the impact on the caregiver in terms of stress, frustration, sleep disorders, anxiety or depression and illness denial-disperception.

The involvement of the psychologist in the telerehabilitation programmes
Patients are randomized into two groups:

- **Group T**: caregivers of patients who will follow telerehabilitation.
- **Group C**: caregivers of patients who will undergo normal rehabilitation training.

Each patient and caregiver will be assessed at T0 and T1:

<table>
<thead>
<tr>
<th>Patient</th>
<th>Caregiver</th>
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<tbody>
<tr>
<td>Quality of life</td>
<td>Burden</td>
</tr>
<tr>
<td>Emotional disorders</td>
<td>Emotional disorders</td>
</tr>
<tr>
<td>Illness denial</td>
<td>Illness denial</td>
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<tr>
<td>Sleep disturbances</td>
<td>Sleep disturbances</td>
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<tr>
<td>Cognitive functions</td>
<td></td>
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**5X1000: THE ROLE OF THE PSYCHOLOGIST**

- **Patient’s assessment:**

<table>
<thead>
<tr>
<th>MOCA</th>
<th>AD-R</th>
<th>PDQ-8</th>
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<tbody>
<tr>
<td>- Cognitive screening</td>
<td>- Anxiety and depressive symptoms</td>
<td>- Quality of life</td>
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<thead>
<tr>
<th>IDQ-R</th>
<th>ISI</th>
<th>ESS</th>
</tr>
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<tbody>
<tr>
<td>- Illness denial</td>
<td>- Insomnia</td>
<td>- Sleepiness</td>
</tr>
</tbody>
</table>
• Caregiver’s assessment:

- **AD-R**
  - Anxiety and depressive symptoms

- **FSQ-SF**
  - Caregiver burden/strain

- **IDQ-R**
  - Illness denial

- **ISI**
  - Insomnia

- **ESS**
  - Sleepiness

• Telesupport for the caregiver every two weeks by telephone
5X1000: SLEEP DISTURBANCES IMPACT

The motor impairment in PD is associated with sleep fragmentation, early awakening, nocturnal cramps and nightmares.

Sleep disturbances are prevalent in PD caregivers.

The poorer is the quality of sleep and the poorer is the quality of life perceived by the caregivers.

(Happe et al., 2002; Cupidi et al., 2012)
PATIENT’S COMMENT

“Essere parte di un progetto di teleriabilitazione, mi fa sentire accolto e seguito”

- More active role in self-management \( (\text{Kenealy et al., 2015}) \)
- Patient satisfaction \( (\text{Wilkinson et al., 2016; Kruse et al., 2017}) \)
- PD patients benefit greatly from multidisciplinary - interdisciplinary medical care \( (\text{Pretzer-Aboff et al., 2015; Ben-Pazi et al., 2018}) \)
The involvement of the psychologist in the telerehabilitation programmes